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UNIVERSITY OF ALBERTA

The Influences for Do-Not-Resuscitate Policies and End-of-Life Treatment or Non-Treatment Decisions

BY

Donna M. Wilson

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of Doctor of Philosophy

Department of Educational Administration,

Edmonton, Alberta

Fall, 1993 ©

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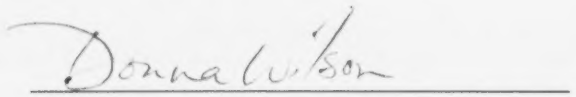

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled The Influences for Do-Not-Resuscitate Policies and End-of-Life Treatment or Non-Treatment Decisions submitted by Donna Marie Wilson in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Educational Administration.

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August 6, 1993

Dedication

This thesis is dedicated to my dear husband, Michael. It could not have been written without his constant support. This thesis is also dedicated our dear daughter Jessica, who has enriched and expanded our lives.

Abstract

A descriptive-comparative study of the influences for DNR policies and end-of-life decisions in acute care and long-term care facilities within Alberta was undertaken in late 1992. 98 of the 135 (72.6%) surveyed accredited health care facilities in Alberta reported having a written DNR policy. The size of facility was significant in relation to DNR policies ($p=.05$); the type of health care facility was not ($p=.72$). Many influences, classified into five categories, were reported by Senior Nursing Administrators to have contributed to the development of DNR policies. Concerns over the decision-making process was the most common influence for DNR policies. The second most prevalent influence was to ensure that the patient would be involved in decision-making. Chart reviews revealed that policies were fully adhered to in only 30.7% percent of cases. Most no-CPR decisions were made when patients were near death and incapable of involvement. Large facilities were more likely to have a DNR policy and to adhere fully to that policy.

All but 11 of the 137 surveyed deceased patients (8.0%) had a no-CPR designation, and all but 4 patients (2.9%) had CPR withheld. Influences for no-CPR decisions were similar to those for DNR policies. The two most common influences for no-CPR decisions were: (a) professional concerns over the outcome of intervention, and (b) family preferences. The no-CPR decision was typically made after a significant proportion of the hospitalization had elapsed. Notwithstanding the prevalence of no-CPR orders, 95 percent of patients died with at least one potentially life-sustaining technology in use. Oxygen supplementation and intravenous infusions were the two most common end-of-life technologies. The use of end-of-life technologies commonly varied in relation to the patient's age, gender, and the type of facility in which they died. The most prevalent influences for end-of-life technology decisions were: (a) professional concerns over the outcome of interventions, and (b) all "other" influences (ensuring the patient's "comfort" was the most frequent intention). In summary, while influences were similar, major shifts in rank and prevalence were observed in the influences for DNR policies, for no-CPR decisions, and for end-of-life technology decisions.

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Chapter I
Introduction

The Dilemma of Life Supporting Interventions

Since 1960, when cardiopulmonary resuscitation was introduced (Kouwenhoven, Jude & Knickerbocker, 1960), the number and sophistication of life supporting interventions has escalated. Underlying these interventions is a societal belief in the absolute value of human life. This societal value, possibly the "sanctity of life" (described by Beauchamp & Childress, 1979; 1989), has been an axiom in the Canadian health care system. Health care was subsequently designed to prevent death, debility, and suffering. There is no doubt that many lives have been saved and much productive capacity of people have been restored through interventions devised to sustain and improve life. However, these same interventions are now being credited with extending the process of dying (Beaton & Degner, 1990; Honan et al., 1988; Miles & Moldow, 1984; Taffet, Teasdale & Luchi, 1988; Younger, 1987).

Common interventions which sustain life, but have the potential to delay inevitable death, include cardio-pulmonary resuscitation (CPR), enteral tube feeding, intravenous fluids and nutrition, peritoneal dialysis and hemodialysis, and mechanical ventilation. Of these, CPR is the most significant as it provides the possibility of life after death. The CPR technique is also so simple, and essentially independent of technology, that it has been widely taught to lay persons, in addition to all health care professionals. Consequently, CPR can be initiated in any setting by almost any person. Furthermore, CPR must be initiated as soon as possible after the cessation of circulation and/or ventilation. Time for reflection is therefore impossible. Other life supporting interventions have much longer potential periods of time in which implementation decisions can be made.

CPR was initially introduced to prevent death from acute reversible cardiac conditions (Evans & Brody, 1985). In these cases, CPR was expected to restore health. A radical and unpredictable change occurred soon after CPR's development however. Quite simply, CPR began to be used whenever a death

occurred. Persons who were experiencing chronic, irreversible, and terminal conditions began to have CPR initiated at the time of their deaths. Clinical criteria other than the cessation of heart activity and/or breathing did not appear to limit the use of CPR. Persons who did not request, or even want, CPR also received it. This change may have resulted from a "mystique" (Godkin, 1992) about the extreme effectiveness of CPR. Belief in the value of human life may have also contributed to the extended use of CPR. Consequently, CPR became a common and well known form of life support.

Most health care facilities today still require CPR to be initiated on any person whose breathing and/or the heart has stopped (Beaton & Degner, 1990; Honan et al., 1988; Miles & Moldow, 1984; Quill, Stankaitis & Krause, 1986; Taffet et al., 1988; Younger, 1987). The exception to this rule is the withholding of CPR when there is a do-not-resuscitate (DNR), or similarly intended, order from a physician. DNR orders originated in the 1970s, and institutional DNR policies, to guide their use, began to be developed soon after (Evans & Brody, 1985; President's Commission, 1983). The common expectation to perform CPR, in the absence of a DNR order, however has continued to precipitate the problem of unrestrained CPR use in health care facilities. According to the U.S.A. Council on Ethical and Judicial Affairs (Council Report, 1991) CPR is still being widely implemented, even when death is inevitable. Consequently, in the majority of cases, CPR has been found incapable of reviving life (Council Report, 1991; Taffet et al., 1988).

The universal employment of CPR is mirrored by the common, and largely unrestricted, use of other life supporting interventions. Enteral tube feeding, the deliverance of artificial fluids and nutrition through a tube, is one noted example. Tube feeding may be implemented whenever a person cannot eat or drink enough to sustain life. Despite obvious short-term and long-term benefits, many researchers have found that tube feeding is initiated when there is minimal likelihood of benefit and there is not even an expectation of benefit (examples: Ciocon, Silverstone, Graver & Foley, 1988; Peck, Cohen & Mulvihill, 1990; Quill, 1989; Wilson, 1991; Wolfsen et al., 1990). Maintenance of life appears to be the goal of tube feeding for many patients (Wilson, 1991).

Life extension may constitute considerable burdens. Massive, irreversible brain damage is a possible, and not uncommon, outcome of CPR (Taffet et al., 1988). The restoration of life, but not an individual's cognitive abilities, is believed by many to be a completely inappropriate application of life support. Furthermore, patients, who are kept alive by tube feeding and other on-going life supports, may never live independent lives. While CPR can initially revive life, life supporting technologies may sustain life for many years (Quill, 1989; Wilson, 1991). Life supporting interventions, if used indiscriminately, can therefore greatly prolong the process of dying. The cost of life supporting technology and of the ongoing care required by patients who have their lives extended in institutions is prohibitive. Other burdens of life supporting interventions are significant and must be considered for a full understanding of the growing controversy surrounding life support.

Chief among these burdens is the physical pain caused by the initiation and ongoing use of life supports. Other forms of suffering may also be introduced or intensified. For example, restraints, which are frequently used to prevent the removal of life supports by patients, cause discomfort and harm from immobility (Quill, 1989). The aging process and disease processes are also not abated by life supporting interventions. The psychosocial effects of extended illness, and imminent death, constitute significant burdens for patients, their families and friends, and even their caregivers.

Unfortunately, many people now feel that an awareness of these negative outcomes of life support occurred after life support had become an integral component of patient care (examples: Anderson, Gladue, Laurie, Skotniski & Tramer, 1991; Johnson & Justin, 1988; Lamm, 1989; Lo, McLeod & Saika, 1986; Macklin, 1989; Rich, 1990; Rozovsky & Rozovsky, 1985). The inherent nature of life support, in a health care system founded on the value of life, may illustrate why there has been minimal appraisal of life support practices. The value of life may also help to explain why there has been limited focus on palliative, or non-curative, care at the end-of-life (MacDonald, 1992). Gaining an understanding of the extent of life support, the reasons for this use, and the

outcomes of that use is therefore urgently required to gain an understanding of the scope of life support utilization.

The evaluation of decision-making processes and other mechanisms designed to optimize the use of life supporting interventions is also in its infancy. The first large scale, and as yet unpublished, survey of DNR policies in Canada was undertaken in mid-1991 (personal communication, P. A. Singer, May 31, 1993). This survey was confined to the extent and focus of DNR policies (personal communication, P. A. Singer, June 23, 1992). Since DNR policies are not mandatory in Canada, the influences for their development are of fundamental interest. Furthermore, whether these DNR policies actually affect end-of-life patient care decisions is not known. Determining if the influences for DNR policies are similar or dissimilar to the influences affecting end-of-life decisions will be helpful for those seeking to investigate and improve the institutional means of preventing life support dilemmas. Gaining an understanding of current end-of-life decision-making processes, and their connections to actual patient care, contributes to a much more complete understanding of life support.

Research Purpose, Main Question, and Sub-Questions

The purpose of this study was to compare the influences from which DNR policies are derived to the influences affecting end-of-life patient care decisions. In particular, DNR policies and practices of end-of-life care were surveyed for descriptive comparative data that answered the following question: Is there a relationship between the influences for DNR policies and the influences for end-of-life patient care decisions? To answer this specific question, data was sought from accredited acute care (AC) and long-term care (LTC) facilities in Alberta to answer eight sub-questions:

1. What are the influences that led to the development of DNR policies in AC and LTC facilities in Alberta?
2. Are the influences for DNR policies similar for all types of health care facilities, or do they differ in relation to whether the facilities are AC

hospitals without intensive care technologies, AC hospitals with intensive care technologies, LTC facilities, or facilities with both AC and LTC beds?

3. Are the influences for DNR policies similar for all sizes of health care facilities, or do they differ in relation to whether the facility is small, medium-sized, or large?
4. Are DNR policies adhered to in facilities where end-of-life care decisions are made?
5. What health care technologies are provided to patients during the end-of-life period?
6. What influences for actual end-of-life patient care decisions are documented in patient care records?
7. What influences for end-of-life patient care decisions are recalled by physicians and nurses involved in the care of DNR patients?
8. Are the influences for DNR policies similar to or do they differ from the influences for end-of-life care decisions?

Definitions

For the purposes of this study, the following terms have been defined. For convenience they have been listed alphabetically.

1. *accredited facility*: an AC hospital or LTC facility that is reported to have met the Canadian Council of Health Facilities (1991) criteria for accreditation.
2. *acute care (AC) hospital/facility*: an institution in Alberta providing active short-term health care to patients.
3. *documented*: written in any part of the patient care record.
4. *do-not-resuscitate (DNR) designation/order*: a written directive in a patient care record which intends to prevent the initiation of CPR and possibly other life supporting interventions.
5. *do-not-resuscitate (DNR) policy*: any written information contained in an AC or LTC facility's policy and procedure manuals which pertains to decisions regarding the withholding of CPR and possibly other life supporting interventions.

6. *end-of-life*: the period which is the longer of the following two periods; the time from when a DNR order was written to the time of a patient's death, or the last week of a patient's life.
7. *end-of-life technologies*: any continuously used equipment or procedures that have the potential to be life supporting, which were used by a patient during the end-of-life period. This excludes CPR.
8. *influence(s)*: one or more factors that have an effect on DNR policy formation and end-of-life care decisions. Influences were reported by SNAs, written in patient care records, or verbally recalled by nurses and physicians.
9. *intensive care technologies*: advanced life support interventions such as ventilators/respirators, cardiac monitors, and other specialty equipment that are used by specially trained health care professionals to combat severe life-threatening conditions. These technologies are only used in association with designated beds in AC hospitals.
10. *large facility*: an AC or LTC facility (excluding bassinets) which has 200 beds or more within its jurisdiction.
11. *life supporting intervention(s)/life support(s)*: terms which refer to any or all current means of extending life. Current life supporting interventions include the CPR technique, and technologies of enteral tube feeding, hemodialysis, and mechanical ventilation systems.
12. *long-term care (LTC) facility*: an institution in Alberta designed to provide ongoing care to patients who reside within that facility.
13. *medium facility*: an AC or LTC facility (excluding bassinets) with 50 to 199 beds within its jurisdiction.
14. *no-CPR order*: a written statement in a patient's chart, which reflects a decision to withhold CPR.
15. *nurse*: a person who has met, and currently holds, registration criteria for nurses in Alberta.
16. *patient*: an adult person (aged 18 or older) who was an inpatient at the time of their demise. This excluded patients who resided in the health care facility for less than one week before their death.

17. *patient care record/chart*: grouped institutional sheets of paper, containing written information that pertains to a specific LTC or AC patient.
18. *physician*: a person who has completed a medical degree and has been licensed to practice medicine in Alberta. Physicians who are general practitioners and specialists are included within this term.
19. *senior nursing administrator (SNA)*: the most senior person, in charge of the department of nursing or the department of patient care in each accredited AC or LTC facility in Alberta; as listed in the Canadian Hospital Association (1990; 1991) Directories of Long-Term Care Centres and Acute Care Facilities.
20. *small facility*: an AC or LTC facility (excluding bassinets) with less than 50 beds within its jurisdiction.

Chapter II
Literature Review

The literature review presented helpful information for substantiating the need for this study, as well as refining its purpose and design. Due to the enormous quantity of literature, only the most relevant research publications, discussion papers, books, and other documents are discussed in this chapter. Attention necessarily focuses on research publications contributing directly to this study.

To initiate this review, a critique of the literature is presented. This critique provides an overview of the trends, major conceptual and methodological focuses, and gaps in the literature. Following this critique, specific literature pertinent to DNR policies and end-of-life care decisions is reviewed. The DNR policy literature review was aided by Dunn's (1984) classification of stages within the policy process. Policies are first developed due to perceived needs or an assessed problem, then implemented, and ultimately are expected to have effects that can be evaluated. The prevalence of DNR policies, influences for DNR policies, and finally the adherence to DNR policies are discussed with these stages in mind.

Following this, the literature focusing on end-of-life treatment and non-treatment decisions is reviewed. This section includes the prevalence of DNR orders, the influences for end-of-life decisions, and the effect of DNR orders on patient care. Five additional topics that are relevant to this study then follow:

1. a comparison of the influences for DNR policies and the influences for end-of-life treatment and non-treatment decisions.
2. the possible relationships between type of health care facility and DNR policy formation or end-of-life patient care decisions.
3. the possible relationships between size of health care facility and DNR policy formation or end-of-life patient care decisions.
4. the conceptual framework guiding this study.
5. the significance of this study.

Critique of Literature

It became obvious during the literature review that life support is a diverse subject. Publications dealt with a wide range of subjects, although the topics of CPR and DNR were among the most common. Another major finding was the divergent views, opinions, and research data for specific life support topics. Few life support topics, if any, have been thoroughly discussed or investigated, and consensus in opinion or research findings reached.

Interest in life support is evident world-wide. Most literature however originates in the U.S.A. It is obvious that there has been and continues to be a great deal of concern over life support there; as precedent-setting legal, ethical, policy, political, and other developments have occurred. A limited number of publications from Europe (notably Sweden and to a lesser degree England), Australia, and Canada are available. The small amount of Canadian life support literature makes it difficult to assess the state of life support in Canada.

Research attention to date has largely focused on improving the craft of specific life supporting interventions. Ever improving life supporting techniques and dissemination of information on these techniques, has no doubt contributed to the prevalence of life support. Few research studies in comparison address the optimization of life support. This relative dearth of research has occurred despite the many discussion papers which advocate the optimization of life support. The earliest papers, which focused on optimizing life support, are dated 1975, 1979, and 1980. Since this beginning, interest has heightened, as is evidenced by an increase in publications. Interest in life support was particularly evident in the mid-1980's, most likely in response to the U.S.A. series of Presidential Commissions on ethical problems in medicine, biomedical and behavioral research. This trend of interest can be expected to continue since life support dilemmas are becoming more prevalent and more visible. These dilemmas will be even more problematic as life supporting interventions become more effective for sustaining life (Lamm, 1989; Jonsen, 1989). Health care costs are also becoming prohibitive (Aroskar, 1987), at a time when life support decisions will need to be made on an ever increasing

basis. The aging of our population and the increasing incidence of chronic diseases are both contributing to this situation (Alberta Senior Citizens Secretariat, 1989; Statistics Canada, 1991; Government of Canada, 1988; National Advisory Council on Aging, 1989; Skelton, 1987).

Most of the research that was reviewed for this literature review is exploratory and descriptive, as expected with a new and largely unresearched topic. Studies tended to have a small number of subjects, and convenience sampling was common. Lack of generalizability is a recurrent limitation. Few qualitative studies are present; quantitative methodologies are most common. Few research papers have substantiated existing theory; instead they have contributed to the generation of theory through improved knowledge of life support.

DNR Policy Literature

Prevalence of DNR policies. It must be emphasized that DNR policies are not required of Canadian health care institutions. The presence of DNR policies could therefore constitute a recognition of need. The prevalence of DNR policies, until recently, has received a limited amount of research attention in Canada. The earliest research reference to an existing Canadian DNR policy was in 1981. McPhail, Moore, O'Connor and Woodward (1981) described the process of policy development in an Ontario AC hospital. Much later, Molloy and Guyatt (1991) evaluated the effect of an institutional directive for end-of-life care planning in one LTC facility in Ontario. More significantly, as indicated, Singer surveyed DNR policies in Canadian AC hospitals. Fifty one percent of all responding AC accredited hospitals had policies pertaining to life support, including DNR policies and policies for forgoing other life-sustaining treatments (personal communication, P. A. Singer, June 23, 1992). The prevalence of AC policies varied between provinces, ranging from 17 to 79 percent. Fifty-seven percent of Alberta AC hospitals reported that they had DNR policies (personal communication, P. A. Singer, May 31, 1993). Following this 1991 survey, Singer then surveyed LTC DNR policies in 1992. No

information is available at this time from this LTC survey, as the data is yet to be completely analyzed (personal communication, P. A. Singer, May 31, 1993).

Most of the DNR policy investigations, and therefore publications, originate in the U.S.A. DNR policies were reported at select U.S.A. health care facilities as early as 1976 (Bedell, Pelle, Maher & Cleary, 1986; Lo, Saika, Strull, Thomas & Showstack, 1985; Miles, Cranford & Schultz, 1982; President's Commission, 1983). Since 1976, DNR policies have become increasingly more common in American AC hospitals. For example: a 1986 survey of AC facilities across the U.S.A. established that 56.9 percent had a formal DNR policy (Longo, Burmeister & Warren, 1988a). Since July 1, 1988, however, DNR policies have been required of every U.S.A. AC hospital by the U.S.A. Joint Accreditation Commission (Edwards, 1990). This requirement will no doubt have increased the prevalence of DNR policies.

LTC facilities in the U.S.A. do not appear to have developed DNR policies as quickly. Between the years of 1984 and 1986, DNR policies were found in 10, 20 and 41 percent of various U.S.A. LTC facilities (Enderlin & Wilhite, 1991; Levinson, Shepard, Dunn & Parker, 1987; Longo et al., 1988a; Miles & Ryden, 1985). Longo, Warren, Roberts and Dunlop (1988b) found significant differences between the prevalence of DNR policies in AC and LTC facilities. A policy was more likely to be found in AC facilities (56.9%) than in LTC facilities (20.1%). There is some belief however, that LTC policies are also increasing in prevalence, due again to the accreditation requirement (Enderlin & Wilhite, 1991; Levinson et al., 1987; Longo et al., 1988a).

American researchers have also suggested that DNR orders are widely accepted and used for patient care purposes in health care facilities. As early as 1983, Miles and Moldow (1984) found 86 percent of Minnesota AC hospitals accepted written DNR orders. Enderlin and Wilhite (1991) similarly found in 1984, that 80 percent of Illinois LTC facilities accepted DNR orders written by physicians. This was notable since only 20 percent of responding Illinois facilities indicated that they had developed written DNR policies. Evans and Brody (1985) also reported that DNR policies did not exist in 3 AC Texas hospitals, however 7 and then 12 percent of patients were found to be

designated as "DNR" in two successive surveys of these facilities. Longo et al. (1988a) reported finding "informal" DNR policies instead of formal written policies in many American AC and LTC facilities, which may explain the acceptance of DNR orders in the absence of DNR policy. Although there has not been a similar survey of Canadian informal policies, it is highly likely that DNR orders, unsupported by a policy governing their use, are also common in Canada. The need for DNR policies is brought to question when DNR orders are found to independently direct care in health care facilities. Underlying this question are the presumed influences for DNR policies.

Influences for DNR policies. The influences for DNR policies do not appear to have been the specific focus of any research investigation. Influences for DNR policies were directly mentioned in only two research publications. Fader, Gambert, Nash, Gupta and Escher (1989) investigated the outcomes of a 1987 New York state law requiring health care facilities to develop DNR policies. Miles and Moldow (1984) demonstrated that the then newly devised Minnesota Medical Association DNR protocol was responsible for state hospitals adopting similar DNR protocols. Professional guides may therefore be as influential for DNR policies as the accreditation requirement (Edwards, 1990). It is also important to mention that one survey revealed why most Illinois LTC facilities in 1984 did not have DNR policies (Enderlin & Wilhite, 1991). Twenty eight percent of administrators reported they were not certain of legal implications, 20 percent felt they were not qualified to write a policy, 16 percent did not feel DNR policies were required for accreditation or other reasons, 11 percent felt no need to write one, 8 percent felt their physicians would not approve of them, 3 percent felt it was incompatible with their culture, and 10 percent mentioned "other" reasons as well.

It is clear that DNR policies are present to some degree in Canadian health facilities, despite accreditation requirements. Although the Canadian Criminal Code, common law court decisions, and Joint Statement (1984) could influence DNR policy formation, these also do not mandate DNR policies. The values, beliefs, and knowledge of health facility administrators and health care

professionals may therefore be influential in policy development, and what the focus and content of that policy is (Hilfinker, 1983). In addition, the intended purpose of DNR policies may simply constitute the basis for their development. For example, Canadian researchers listed these reasons for DNR policy development: "to ensure that physicians decide on the appropriateness of resuscitation attempts before it is needed; to have each physician consult his or her patients or the families of incompetent patients; ...and to provide legal protection for physicians and the hospital" (McPhail et al., 1981, p. 830).

Evidently the intended purpose or purposes of DNR policies varies widely, regardless of what country the policy is found in. Smith and Veatch (1987), editors of the precedent setting textbook "Guidelines on the Termination of Life-Sustaining Treatment and Care of The Dying", felt that the controversial nature of decisions to forego medical procedures and the potential for abuse demanded written policies in health care institutions. Levinson et al. (1987) instead felt DNR "policies are designed to increase patient, family, and hospital staff comfort (with DNR orders); and to improve the quality of patient care" (p. 1059). Shelley, Zahorchak and Gambrill (1987) contend that DNR policies need to address the needs of critically ill patients who require decisions about the use of CPR and other life supporting interventions. Perkins (1986) similarly suggested that DNR policies encourage the use of DNR orders for select patients. Through providing appropriate patient care, policies are thought to provide a measure of legal protection for the health care facility and health care professionals (McPhail et al., 1981).

Physicians, in particular, receive guidance in their decision to limit resuscitation efforts (McPhail et al., 1981). Physicians are key participants in resuscitation decisions, as frequently they are the only health care professionals responsible for ordering end-of-life interventions. Quill et al. (1986) felt policies "help physicians share with their patients the burden of limited resuscitation and offer patients increased self-determination and more appropriate utilization of medical technology" (p. 622). LTC facilities commonly have DNR policies which prohibit transfer of patients to AC hospitals where aggressive life supporting interventions are likely to ensue (Brown & Thompson,

1979; Enderlin & Wilhite, 1991; Fader et al., 1989; Levinson et al., 1987). Miles et al. (1982) felt DNR policies "ensure that the decision is made through a medically responsible, ethical, and sensitive process that protects the rights of patients and families, and that there is adequate communication between those involved in the patient's care" (p. 660). They suggest there is no standard criterion for decision-making, as the physician should weigh the "unique set of facts and issues present in each case" (Miles et al., 1982, p. 663). The Canadian Joint Statement (1984) for terminally ill patient care however outlines simple clinical criteria on which to base no-resuscitation decisions.

The appropriate timing of resuscitation decisions is also a key purpose of policies (Beaton & Degner, 1990; Bedell et al., 1986; Dunaway, 1988; Honan et al., 1988; Levinson et al., 1987; McPhail et al., 1981; President's Commission, 1983). Furthermore, in Hackler and Hiller's (1990) opinion, a policy should prevent surrogate decision-makers from forcing undesirable treatment on incompetent patients. Many others, however, assert that policies mandate the patient or surrogate as the decision-maker (Bedell et al., 1986; Dunaway, 1988; Honan et al., 1988; McPhail et al., 1981; Levinson et al., 1987). Patients' rights therefore tend to be a key component of many policies. In summary, it appears that there are many possible purposes for DNR policies. These purposes may vary between facilities, and may affect the need for a policy and the degree of adherence to that policy.

The focus of the DNR policy could also be a factor in policy development and later policy adherence. As indicated, a DNR policy may only narrowly apply to the withholding of CPR (Bedell et al., 1986; Lewandowski, Daly, McClish, Juknialis & Younger, 1985; Shelley et al., 1987). However, CPR is only one treatment decision that must be made; other potential forms of life support commonly require decisions as well (Frampton & Mayewski, 1989; Miles & Moldow, 1984; Quill et al., 1986; Younger et al., 1985). Singer determined that only five percent of DNR policies AC facilities across Canada pertained to life supporting interventions in addition to CPR (personal communication, June 23, 1992). Similarly, in 1983, 8 percent of Minnesota AC hospitals had a broad resuscitation policy in comparis to another 44 percent

which had only a narrow CPR focused policy (Miles & Moldow, 1984). Broader DNR policies have been called supportive care protocols (Miles & Moldow, 1984), levels of care (Quill et al., 1986), and comprehensive health care directives (Molloy & Guyatt, 1991). Broader policies may be an improvement over policies singularly focused on CPR, since they promote open dialogue about the full range of treatment options (Frampton & Mayewski, 1987).

This variance in focus of DNR policies, however, could potentially create communication problems. Honan et al.'s (1988) investigation of how American nurses, physicians, and lay-persons defined the term "DNR" illustrates this. Significant variations were found to exist between and within groups. Diverse opinions about withholding any or all of the following life supporting interventions were found: CPR, ventilator, emergency drugs, antibiotics, intravenous fluids, and artificial feeding. DNR policies, at the very least, should standardize what the term DNR means (Honan et al., 1988; Miles & Moldow, 1984; Shelley et al., 1987). If the DNR policy focus is not clearly understood, policy development and later adherence would be adversely affected. In summary, the direct and indirect influences for DNR policies are numerous. The development of DNR policies may be dependent on these influences for DNR policy.

Adherence to DNR policies. In general, the subject of adherence to DNR policies has received limited attention. Assumptions that DNR policies direct practice would negate the need for investigations of compliance. Variable adherence to DNR policies however has been shown; for example, the Canadian study by McPhail et al. (1981) found only 57% of AC nurses, physicians and other staff had read and felt they understood a DNR policy implemented one year before. Honan et al. (1988) similarly found only 18 percent of American nurses knew if their hospital had a DNR policy, although 97.3 percent of them believed a DNR policy was essential. It would be difficult to follow a policy if there was little or no knowledge of that policy.

In contrast, Lo et al. (1986) determined that a DNR policy in one American hospital, which simply required physicians to write a DNR order in the chart,

was "usually" adhered to. This suggests that the content of DNR policies may be an influence in policy adherence. DNR policies commonly outline "sensible procedures for implementing the DNR order" (Perkins, 1986, p. 171). Two surveys have described the procedural content of policies. Longo et al. (1988a) listed DNR policy content, surveyed across American LTC facilities: documentation of the order (93%), who would write the order (91%), involvement of patient or surrogate (91%), patient competency (73%), evidence of informed consent (71%), ongoing discussion with patients and surrogates (71%), and discussion of the DNR order with facility staff (70%). Miles and Moldow (1984) also reported the content of DNR policies in their survey of AC hospitals in Minnesota. AC policies: defined DNR (85%), allowed aggressive medical care (78%), suggested review or renewal of the DNR order (74%), stated a patient's right to consent (69%), and gave medical criteria for a DNR order (7%). These policies commonly mirrored the Minnesota Medical Association's guidelines for DNR policies. The President's Commission (1983), on Foregoing Life-Sustaining Treatment, also contains guidelines for DNR policies which may have been influential for the content of DNR policies across the U.S.A. Similarly, the 1984 Joint Statement on Terminal Illness provides simple procedural guidelines that may be reflected in Canadian policies.

More complex procedural policies may be more difficult to adhere to. For example, Bedell et al. (1986) investigated compliance with an American AC hospital DNR policy. Documentation, one of the policy's requirements, increased significantly, from 50 percent to 82 percent, over a 4 year period. The policy's fundamental goal of involving patients in decision-making was not met however, as DNR orders were usually written when patients were incompetent and near death. Furthermore, CPR and other forms of life support were commonly withheld after a patient was designated DNR, despite the policy's sole focus on CPR. As indicated, the exact content of the policy may be a factor in adherence to the policy. The development of a policy may also be facilitated or hampered by the intended content of the policy.

Not only can health care professionals be variably compliant with DNR policies; surrogate decision-makers have also been found non-compliant with a

new policy that mandated their involvement. Surrogates were asked to designate resuscitation status for their demented family members in an American LTC facility (Fader et al., 1989). During the three-month study, which started immediately after the policy was implemented, 45 percent of surrogates did not reply to repeated correspondence from the facility. In a more recent Canadian study, Molloy and Guyatt (1991) found that only 7 percent of patients and 5 percent of surrogates would not make end-of-life resuscitation decisions. Differences in legal and financial implications of involvement in the U.S.A. and Canada may explain these variable findings. The recent "death with dignity" movement (Addison, 1991) may also be significant in explaining an increased willingness of families to be involved and thus compliant with a DNR policy. However, wives have been found to have highly inaccurate perceptions of their husbands' resuscitation preferences (Uhlmann, Pearlman & Cain, 1988). In a recent Canadian study, Wilson (in press) also found a surrogate decision-maker could not surmise her mother's values and preferences in making a life support decision. This surrogate was required to make a decision about implementing tube feeding (or allowing death to occur). Her mother had been severely mentally impaired for many years and was unable to participate in decision-making. The variable willingness and ability of patients to be involved in end-of-life decision-making has also been noted in other investigations, although patient compliance has not generally been considered in investigations of policy adherence. A more complete description of patient involvement will follow in the end-of-life decision section.

The effect of DNR policies on health care personnel may also be a factor in adherence. McPhail et al. (1981) reported that 60 percent of Canadian physicians in one AC facility found a DNR policy was helpful, while 28 percent felt it had not affected them, and 12 percent felt it was not helpful. No further details were given about what constituted helpfulness or unhelpfulness. Perkins (1986), an American physician, related that a DNR policy was not helpful in making an ethically problematic resuscitation decision for a specific patient. In contrast, Levinson et al. (1987) found 70 percent of administrators in American LTC facilities, where there was no DNR policy, wished they had

one (reasons for this were not outlined). Honan et al. (1988) also found 97.3 percent of surveyed American nurses believed a DNR policy to be essential. Nurses, due to their proximity to patients, are most likely to be the individuals who initiate resuscitation in the absence of DNR orders. Many Canadian and other nurses have reported that DNR policies reduce their frustration over a lack of DNR orders and the all-too-common late timing of DNR decisions (Beaton & Degner, 1990; Shelley et al., 1987; Townsend, Vass & Defontes, 1990).

Clinical data, indicating the effect of policy and indirectly the adherence to DNR policies, is also minimal. Quill et al. (1986) found a significant increase in DNR orders for patients over the age of 80, and a nonsignificant decline in the incidence of CPR after a DNR policy had been implemented in one New York state AC hospital. Longo et al. (1988a) also concluded their survey of DNR policies by indicating that more thoughtful discussions over resuscitation ensue because of DNR policies.

In summary, it can be surmised that DNR policies are helpful for optimizing life supporting interventions, but they may be disregarded in full or in part. The outcomes may therefore differ from what was intended by policy. Berman (1978) called this "slippage", since outcomes may slip away from intentions during implementation. Simplicity, long-term presence, and content of DNR policies may be significant factors in adherence. Despite a reluctance to develop DNR policies in some health care organizations (Enderlin & Wilhite, 1991), an increasing prevalence of DNR policies is clearly the trend. Influences for DNR policy development must account for this trend, since there is little evaluative evidence of adherence to or even benefit of DNR policies.

End-Of-Life Treatment and Non-Treatment Decisions Literature

Prevalence of DNR orders. Available information on end-of-life decisions is usually limited to the prevalence of DNR orders, the incidence of CPR, and the Intensive Care Unit (ICU) treatment of DNR patients. Various studies have established that a range of 3 to 12 percent of all patients in U.S.A. AC hospitals are designated "DNR" (Bedell et al., 1986; Evans & Brody, 1985; Lo et al., 1985;

Lipton, 1986; Schwartz & Reilly, 1986). Five studies have furthermore confirmed that 66 to 75 percent of all deaths are among DNR patients in American AC hospitals (Bedell & Delbanco, 1984, Bedell et al., 1986, Lipton, 1986; Schwartz & Reilly, 1986; Taffet et al., 1988). This disproportionately high rate of death in DNR patients indicates the importance of the role of DNR orders and perhaps DNR policies in patient care.

Patients, who are unlikely to benefit from resuscitation, appear to more commonly receive a DNR designation. Although controversial, older persons and chronically ill persons requiring long-term institutional care may constitute a group that would not benefit from resuscitative efforts. The incidence of DNR orders for patients in LTC facilities, however, has rarely been reported. Wolff, Smolen and Ferrara (1985) found only one patient in a 200-bed U.S.A. nursing home had a formally designated DNR status in 1983. A later study, by Fader et al. (1989), found 37.5 percent of competent American LTC patients chose a DNR designation over resuscitation. Twice as many surrogate decision-makers however chose the DNR designation over resuscitation for their incompetent relatives in that LTC facility. More recently, Wilson (1991), in a Western Canadian study, found seven out of ten tube fed patients in one LTC facility had a DNR order. Addison (1991) also reported that 89.5 percent of 466 patients in one Alberta LTC facility chose or were designated "no CPR" by surrogate decision-makers. Molloy and Guyatt (1991) similarly reported that following the development of a DNR policy, 82 percent of competent patients in one Ontario LTC facility requested that CPR not be initiated if cardiac arrest occurred. The most recent resuscitation trend in Canada appears to involve resuscitation decisions made, as a matter of course, for all patients on admission to LTC facilities (Molloy & Guyatt, 1991).

Another group of persons who may be expected to have DNR orders are those who are seriously or terminally ill. A great deal of debate has occurred over DNR patients in ICU. DNR orders may be highly appropriate for ICU patients, since most AC hospital deaths are in the ICU. Mumma and Benoliel (1984-85) found 52.7 percent of patient deaths occurred in one hospital's ICU, with fewer deaths (33.7%) occurring among the substantially more medical and

surgical patients. Lewandowski et al. (1985) also reported that American DNR patients were frequently treated and died (without CPR) in an American ICU. However only 30 to 39 percent of all patients in various U.S.A. ICUs have been found to have DNR orders (Witte, 1984; Zimmerman, Knaus & Sharpe, 1988). Few patients (14%), furthermore, have DNR orders written while they are there (Lewandowski et al., 1985; Younger et al., 1985; Zimmerman et al., 1988). Younger et al. (1985) also noted that DNR patients in an ICU consumed comparable amounts of resources to non-DNR patients in that ICU, and that DNR patients had consumed more resources (than non-DNR patients) before the DNR order. The life saving technologies available in ICUs may contribute to limited discussions about withholding resuscitation. After all, the purpose of the ICU is to be aggressively life supporting.

The willingness of physicians and nurses to admit DNR patients to ICU's has been revealed repeatedly. For example, Shelley et al. (1987) surveyed a wide range and number of American nurses and found that the majority still believed DNR patients should be aggressively nursed and might be appropriate candidates for the ICU. Vincent (1990) also found two-thirds of the surveyed European physicians would admit patients, who were expected to die within the next few weeks, to the ICU. Unfortunately, information on the presence of DNR patients in Canadian ICUs and the attitudes of Canadian health care professionals or laypersons about ICU care for DNR patients does not appear to exist.

The prevalence of specific technological interventions during the end-of-life period also does not appear to have been researched. It can only be speculated how many DNR or dying patients receive tube feeding, peritoneal and hemodialysis, oxygen, intravenous fluids and medications, or other ongoing forms of life support. Much less is therefore known about the prevalence of DNR orders and technological care at the end-of-life, in comparison to the prevalence of DNR policies. This situation has occurred despite overwhelming legal and ethical interest in the use of life supports. As a result, the technological support required by dying persons remains diverse, unfocused, and perhaps too often "life" oriented.

Influences for end-of-life decisions. Many influences for end-of-life decisions were found in the available life support literature. It was evident however that few distinctions between decisions to limit CPR, and to either limit or administer other potentially life supporting end-of-life interventions are made. It may be that the influences are similar regardless of whether the decision is about CPR or about other potentially life sustaining interventions. Three groups of influences appeared most commonly in the literature: physicians as decision-makers, ethical reasoning of health care professionals, and patient characteristics. Other influences, some of which have been identified, may also play a significant role in end-of-life decisions. One such possible influence is clinical criteria for these decisions.

Despite its importance, research-based clinical criteria for making end-of-life decisions generally does not exist (Chipman, Adelman & Sexton, 1981; Dunaway, 1988). As early as 1980, there were recommendations to develop objective clinical criteria for guiding aggressiveness of patient care (Bexell, Norberg & Norberg, 1980). Some research has attempted to address this deficit. Bedell, Delbanco, Cook and Epstein's (1983) investigated factors significant in whether 294 patients in one American AC hospital were successfully or unsuccessfully resuscitated. Patients with pneumonia and those who had resuscitation that lasted longer than 30 minutes did not live to be discharged from hospital. Hypotension, renal failure, cancer, and a home-bound life style were also significantly associated with mortality. The age of patients was not found significant for survival.

Stereotypes of aging and institutionalization may influence clinical decisions. Chipman et al. (1981) found 18 percent of American emergency physicians reported they would stop CPR if it had been initiated on patients who had been transferred from a nursing home. Taffet et al. (1988) reported that age was clinically significant for CPR success, as patients who were older than 70 years of age did not live to be discharged after CPR had been administered. Only 16 percent of younger patients however lived to be discharged after CPR had been given. The presence of fever, cancer, high use of medications during the CPR episode, and absence of witnesses at the time of

cardio-pulmonary arrest were also related to increased incidence of death. Finally, Tittle, Moody and Becker (1992) have recently completed a study to identify variables for predicting DNR orders and the nursing care of these ICU patients. The severity of illness was identified as a key variable.

Determining outcomes of interventions, in advance, is difficult and perhaps not even feasible (Berman, 1978). Furthermore, withholding and withdrawing life supporting technology is very arduous for all involved, which can make objective decisions difficult. Peck et al. (1990), Wilson (1991), and Wolfsen et al. (1990) all point to an absence of valid outcomes for life supporting technology in dying patients. Maintenance of life may be the only outcome of life support (Peck et al., 1990). There is no doubt that end-of-life patient care decisions are supposed to be rational, as well as ethically and culturally correct. Alemaychu et al. (1991), for example, listed factors that physicians should consider when they are making treatment decisions, "the wishes of the patient and his or her family, the patient's prognosis, age, and quality of life, the legal implications of giving or withholding care, the institution's policy, the cost and availability of health care resources, and the prevailing cultural and social norms" (p. 113). In addition, in Hilfinker's (1983) opinion, the subjective feelings, prejudices, and moods of health care professionals, patients, and family members may be very significant in end-of-life decisions and subsequent care.

As has already been indicated, physicians were repeatedly found to be the principal decision-makers regarding end-of-life interventions (examples: Beaton & Degner, 1990; Davis & Slater, 1989; Ott & Niewiadomy, 1991; Perry, Schwartz & Amchin, 1986; Quill, 1989; Schwartz & Reilly, 1986; Slater, 1987; Vincent, 1990; Wilson, 1991). Research has also shown that, given the same clinical information about a patient, varying treatment options will be chosen by individual physicians (examples: Alemaychu et al., 1991; Brown & Thompson, 1979; Chipman et al., 1981; Farber, Bowman, Major & Green, 1984; Pearlman, Inui & Carter, 1982; Pearlman & Jonsen, 1985). Due to this variance in decisions, physician characteristics have understandably been the subject of considerable research. The age, personal religion and degree of faith

of physicians; their speciality, educational background, residency training and experiential base; their fear of legal suits; and also the culture and expectations of the country they practiced in were found potentially, but not always, to be associated with treatment decisions (Alemaychu et al., 1991; Chipman et al., 1981; Crane, 1975; Farber et al., 1984; Pearlman et al., 1982; Thom, 1988). A particular study by Bedell and Delbanco (1984) contains additional relevant information. They found that the level of physician training and physician's estimate of probability of patient arrest did not influence whether the physician discussed resuscitation with the patient, since it was uncommon for doctors and patients to ever discuss resuscitation. Instead, physicians formed an opinion about what they believed the patient wanted. The validity of these opinions was investigated, and only a weak correlation was found.

Other studies have focused on the ethical reasoning of health care professionals for end-of-life decisions. Despite the established significance of physicians in end-of-life decision-making, there does not appear to have been much investigation of their ethical reasoning. Pearlman et al. (1982) approached the ethical reasoning of physicians in his study, entitled "Variability in Physician Bioethical Decision-Making". Physician decisions, however, were found to have been based on whether the patients had acute reversible illnesses or not. The ethical reasoning of patients or families for end-of-life decisions also does not appear to have been assessed. The ethical reasoning of nurses, in comparison, has frequently been appraised. It is interesting that this line of investigation exists, since research has not established the involvement of nurses in end-of-life decisions (examples: Beaton & Degner, 1990; Davis & Slater, 1990; Keffer, 1990; Wilson, 1991).

A principle-oriented conceptual framework (originally outlined by Beauchamp and Childress in 1979 and by others) has commonly guided past investigations of moral reasoning. The central thesis of principle-oriented ethics is the universal and rational application of principles such as justice, autonomy, and beneficence (Fry, 1989). Principles are certain, unchanging, and fundamental standards whose "existence is independent of human choice and experience" (Ackerman, 1983, p. 172). The principle of patient autonomy

was found to be the most important principle guiding nurses' opinions about appropriate end-of-life patient care (Davis & Slater, 1989, Jansson & Norberg, 1989; Norberg, Asplund & Waxman, 1987a; Slater, 1987). Both the principles of autonomy and beneficence were deemed to be important guides for nurses who would potentially force feed severely demented patients (Akerlund & Norberg, 1985).

The rights, and duties or obligations of people also appear to be based on these principles (Omery, 1989) or the values that contribute to these principles. For example, a key ethical study was a 1984 survey of Israeli health caregivers (Norberg & Hirschfeld, 1987b). Sanctity of life was the predominant ethical value influencing end-of-life decisions in Israel. Norberg, Norberg, Gippert and Bexell (1980) similarly found that Swedish caregivers felt they had a professional duty to sustain life. Perceived professional obligations appear to be very influential in end-of-life patient care decisions.

The principle-oriented ethical framework has recently been criticized for not being readily applicable to health care practice (Ackerman, 1989; Huggins & Scalzi, 1988; Marshall, 1992; Omery, 1989, Penticuff, 1991; Toulmin, 1991; Wear, 1991). One of the most important criticisms of principle-oriented ethics is its lack of attention to the context or "whole" situation. The principle-oriented ethical theory is now being contrasted with a relational, caring, or contextual ethical theory developed by Carol Gilligan in 1982 (Blum, 1988; Carse, 1991; Fry, 1991, Houston, 1989; Marshall, 1992; Noddings, 1984).

The theory of "relational caring" may help to identify additional influences and contradictions in end-of-life patient care decisions. As early as 1977, Brown and Thompson (1979) found physicians who were familiar with LTC patients would treat fevers less often, in comparison to physicians who were filling in and were thus unfamiliar with patients. Patients who required more nursing care were also less likely to be treated if they developed high fevers. The health care professionals who had ongoing relationships with the patients were less likely to intervene when life-threatening fevers developed. In another study, Watts, Cassel and Hickam (1986) found that nurses, more than physicians, were more likely to want to carry out tube feeding when their

elderly LTC patients could no longer eat. The proximity of nurses and patients and the ongoing nature of their relationships, were felt to be significant in the reasoning for initiating life support. Three other studies suggest the importance of caring relationships in end-of-life decisions (Cooper, 1991; Danis et al., 1991; Jansson & Norberg, 1989).

As has been indicated, the physician as decision-maker, the ethical reasoning of health care professionals, and patient characteristics were found to be the most common influences outlined in the literature. These influences are significant since valid clinical criteria on which to base end-of-life decisions does not appear to have been developed. Other influences for end-of-life decisions can be surmised to exist. Specific professional or other key documents developed to date may have been influential. Changes in patient care decisions, for example, may have occurred after DNR policies were found to have been widely developed and based on the Minnesota Medical Association Guidelines (Miles & Moldow, 1984). The Canadian Joint Statement on Terminal Illness (1984) and the U.S.A. President's Commission of the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, in particular "Deciding to Forego Life-Sustaining Treatment" (1983) may have also been very influential in end-of-life care decisions. There is, however, no research basis for this claim.

DNR or other similar legislation may also greatly affect end-of-life patient care decisions. Only one study by Quill (1989) appears to have investigated the effect of a state law on patient care. The law was not found instrumental in increasing the involvement of patients in decisions about resuscitation. Few laws in Canada pertain specifically to life support, which limits research attention to the impact of laws on patient care. One recent Canadian case, however, is believed to have made a major impact on the right of patients to be self determined. Nancy B., a young woman in Quebec, recently had her life supporting ventilator removed after appealing to the courts. Withdrawal occurred despite her physician's and hospital's attempts to prevent it (Deacon & Came, 1991). Existing Canadian criminal law, prohibiting both murder and assistance with suicide attempts, had contributed to the reluctance to

withdraw life support in her case. Another recent common law case, Malette v. Shulman (1990), has also supported self-determination for Canadian patients. An unconscious woman of the Jehovah Witness faith was treated with blood at an Ontario AC hospital, despite a card being found specifying her wishes not to be given blood in any circumstances (Skelton, 1990). Her rights to self-determination were later upheld in court. Blood should not have been given against her competent wishes, despite her incompetency at the time and her probability of death without this intervention.

The continuing shift to patient autonomy, beginning with the legal awareness of patient's rights in the 1970's, has been identified as a factor in end-of-life treatment decisions. This trend was initially investigated by two 1976 surveys of American physicians (Carey & Posavac, 1978-79; Noyes, Jochimsen & Travis, 1977). More openness in patient-physician communication was already found at that time. Some authors argue that patient self-determination is the most important factor in life support decision-making today (Macklin, 1989; Wear, 1991). Patients have been found to be generally interested and willing to participate in care decisions. For example, Godkin (1992) found 85 percent of competent elderly institutionalized patients in one AC and one LTC facility in Western Canada wanted to be involved in decisions about resuscitation. Despite apparent willingness, patient involvement in decision-making is still not ensured (research examples of this: Bedell & Delbanco, 1984; Bedell et al., 1986; Frampton & Mayewski, 1987; Frankl, Oye & Bellamy, 1989; Godkin, 1992; Johnson & Justin, 1988; Lo et al., 1986; Perry et al., 1986; Schwartz & Reilly 1986; Shmerling, Bedell, Lilienfeld & Delbanco, 1988; Thom, 1988; Vincent, 1990; Wetle, Levkoff, Cwikel & Rosen, 1988).

Besides the problem of patients not being involved in resuscitation decisions, surrogate decision-makers may lack information for decision-making and the opportunity for involvement. For example, 30 percent of families were notified after their elderly family member had been transferred from an LTC facility to an AC hospital (Wolff et al., 1985). These families then had no opportunity for involvement in decisions to withhold initial AC treatments.

Traditionally organized health care facilities and stasis of organizational change may be additional factors perpetuating low patient and family involvement. Beaton and Degner (1990) investigated the impact of life support dilemmas on Canadian nurses, and found the sole right of physicians to make DNR decisions had a great impact on nurses, and subsequently on patients and families. Nurses were placed in a difficult and stressful position when a DNR order was not written but should have been. Patients and families may have said that they did not want CPR performed, but nurses were compelled to do CPR if a DNR order was not written. Nurses may have also determined that resuscitation was inappropriate but again felt they were required to carry out CPR if a DNR order was not present. Similarly, head nurses in one U.S.A. LTC facility did not feel AC hospitalization was appropriate for 37 percent of their patients who had been transferred to an AC hospital (Wolff et al., 1985). They could not prevent the transfers after they had been ordered by a physician.

Nurses, patients, and/or their families had been found involved (to varying degrees) in end-of-life decision-making however (examples: Brown & Thompson, 1979; Ciocon et al., 1988; Dunaway, 1988; Keffer, 1990; Molloy & Guyatt, 1991; Witte, 1984). Nurse and surrogate characteristics, as well as patient and physician characteristics, may therefore be influential for end-of-life decisions. Only a few studies have explored this topic, unfortunately. Bedell et al. (1986) found that families were influenced by four factors when they were making DNR decisions. These factors included learning that the patient was in a coma or was brain dead, having support from physicians and nurses during decision-making, having ongoing assurance that appropriate care would continue despite a DNR decision, and also whether they had a prior discussion with the patient about their treatment preferences. Fader et al.'s (1989) study established that surrogates made resuscitation decisions based largely on the age of the patient. Ciocon et al. (1988) found some LTC patients had been kept alive only on the express and controversial wishes of family members. The reasoning of these family members was not illuminated however.

It may be much easier to decide to implement life support than it is to withhold or withdraw life support. People may be unwilling decision-makers for

others when the required decision is to limit life supporting interventions (Fader et al., 1989). Steiber (1987) surveyed members of the public and found that only 72 percent of Americans were "willing" to disconnect life-supports for relatives. Twenty-eight percent were unwilling or undecided about the decision to stop treatment.

It must also be noted that there is great variation in what patients (and perhaps their families) feel are acceptable treatments (examples: Bedell & Delbanco, 1984; Fader et al., 1989; Frankl et al., 1989; Godkin, 1992; Johnson & Justin, 1988; Starr, Pearlman & Uhlmann, 1988, Shmerling et al., 1988; Steiber, 1987; Steinbrook et al., 1986; Uhlmann et al., 1988). In particular, Godkin's (1992) Canadian study found the majority (65%) of elderly patients wanted to have CPR performed, while other patients were uncertain or unwilling to have it performed. The reasons for the decision to have CPR implemented were commonly and simply related to a desire to live. Fear of brain damage was the major deterrent for those who did not want to be resuscitated. Other studies have reported numerous and variable personal characteristics of patients; no common pattern is yet apparent nor likely to be apparent (examples: Bedell & Delbanco, 1984; Fader et al., 1989; Frankl et al., 1989; Godkin, 1992; Johnson & Justin, 1988; Pearlman & Uhlmann, 1988; Starr et al., 1986, Shmerling et al., 1988; Steiber, 1987; Steinbrook et al., 1986; Uhlmann et al., 1988).

Advance treatment directives (ATD) may be one method of ensuring individual patient preferences. The Alberta Law Reform Institute (1991), instrumental in advocating ATDs for Alberta, defines an ATD as a document that "expresses the writer's preferences and instructions with respect to medical treatment" (p. 10). For this reason, these documents have also been called "living wills" (Robertson, 1991, p.3), although ATDs are normally considered broader in scope than living wills. To date, ATDs are not legally binding in Canada (Alberta Law Reform Institute, 1991; Anderson et al., 1991; Bolton, 1989). Recent Canadian interest in ATDs may be due to their endorsement in late 1990 by the U.S.A. Federal Self Determination Act (In Brief, 1991). This Act requires that all health care facilities receiving federally

derived funds, ask patients on admission whether they have an ATD. Most American states have had ATD legislation as early as 1977 (President's Commission, 1983). ATD legislation may be implemented in Alberta as early as 1993.

Despite a current lack of legal support in Canada, some health care facilities and physicians do recognize the existence of ATDs and use them to guide end-of-life care decisions (examples: Alemaychu et al., 1991; Molloy & Guyatt, 1991). The proposed legislation in alberta would encourage Albertans to consider developing ATDs, and would help to ensure that ATDs are recognized and used by health care professionals in health care facilities (Alberta Law Reform Institute, 1991). ATDs usually incorporate (a) actual preferences for care, and (b) the name of a surrogate decision-maker. A group of Canadian nurses (Anderson et al., 1991) advocate ATD's, since they feel ATDs offer patients the right to control their own quality of life and dignity in dying. Legislative approval of ATDs should therefore increase discussions among lay persons about end-of-life treatment preferences.

The importance of ATDs is suggested by research findings where end-of-life planning is frequently left until death is near and patients are incompetent (Bedell & Delbanco, 1984; Bedell et al., 1986). Patient incompetency requires that other persons become surrogate decision-makers (see Frampton & Mayewski, 1987; Lo et al., 1985). End-of-life care is all too frequently more reflective of family and physician preferences and values (examples: Alemaychu et al., 1991, Bedell & Delbanco, 1984; Bedell et al., 1986; Brown & Thompson, 1979; Chipman et al., 1981; Crane, 1975; Davis & Slater, 1989; Enderlin & Wilhite, 1991; Fader et al., 1989; Perry et al., 1986; Quill, 1989; Thom, 1985; Wilson, in press; Witte, 1984; Wolff et al., 1985).

Few studies have investigated the incidence of ATDs however. In a 1986 gallup poll, 9 percent of Americans reported having a written ATD (Steiber, 1987). Steinbrook et al. (1986) also found ATDs were significantly more common after men had been ill or had been hospitalized because of AIDS. Davidson, Hackler, Caradine & McCord (1989) surveyed attitudes and experiences of Arkansas physicians toward ATDs in 1988-89 (n=1293).

Arkansas was one of the first states to have ATD legislation, commencing in 1977. Eighty percent of responding physicians (65% return rate) were positively disposed to ATDs and only two percent were negative toward them. The majority (55.9%) had experience with ATDs, and 83.5 percent of these physicians reported they had become more positive toward them because of their experience. The 1990 Federal legislation endorsing ATD use in health care facilities (In Brief, 1991), and the publicity surrounding Nancy Cruzan's right-to-die case in 1990 (Guarino & Antoine, 1991) may have since increased the incidence of ATDs in the U.S.A.

The impact of ATDs has also been of interest to some researchers. Dunaway (1988) reported that in 1986, three out of seven American AC hospitals did acknowledge ATD's in decisions about ICU patient care. Witte (1984) also said that the documentation of family preferences was important when later decisions were made. In particular, documented family wishes were the only variables, among many, which were found significantly different between ICU patients who were resuscitated and those who were not. Molloy and Guyatt (1991) also reported that in the year following implementation of an ATD system, fewer LTC patient deaths occurred in AC hospitals and there was a significant reduction in the mean length of AC hospital stay for the LTC patients who had been transferred there. Patients furthermore did not change their ATD over time, despite changes in their health and other circumstances. Alemaychu et al. (1991) also investigated the attitudes of physicians in seven different countries (including Canada) toward ATDs and found that 40 percent of physicians would not follow all of the directives in an ATD. In 1987, 36 percent of 2000 surveyed Ontario physicians reported they would not follow all aspects of ATDs (Goddard, 1988). Danis et al. (1991) also found that 25 percent of ATDs were not followed when LTC patients became seriously ill. It is possible that ATDs may not be unambiguous enough to direct specific patient care decisions after a patient is incompetent. Steiber (1987) also found 28 percent of Americans polled would not want to be surrogate decision-makers. It may be that potential surrogates do not know the preferences of their relatives and so were reluctant to become surrogates. Another interesting

finding about ATDs was noted in Longo et al.'s (1988a) report of their America-wide health care facility survey. If a health care facility recognized ATDs this was negatively associated with the presence of a DNR policy.

In summary, many influences could affect end-of-life treatment or non-treatment decisions. It is not at all evident that all possible influences have even been identified. For example, Younger et al. (1985) reported finding written justifications for DNR decisions in only 58 percent of patient care records. A fear of litigation may have led to an absence of documentation and would hamper research efforts to harvest information on influences. The complexity and sensitivity of life support decisions may have also suppressed efforts to explore and describe influences. Research efforts to gather information on influences may therefore suffer from design problems. Conceptual frameworks based on principle-oriented ethics, for example, may not account for the complexity of end-of-life treatment decisions. Studies using contextual ethics instead may capture more obscure but important influences. Influences may also confound each other, so their impact on decisions may or may not be constant. It is not surprising that decisions vary when many competing decision-making factors must be considered. Decision-making is not a simple process. It would appear that Ackoff (1974) and Mitroff (1983) are correct; problems that require policies are frequently "messy" and "wicked".

Effect of DNR designation on patient care. Research investigations of the effect of a DNR designation on patient care are more common than those of the effect of DNR policies on patient care. However, available information on the outcomes of DNR decisions is essentially contradictory. DNR orders may have little effect on treatment decisions or they may contribute to the withholding of CPR, as well as many other potential treatments. For example, Bedell et al. (1986) reported that 28 percent of all patients in one U.S.A. AC hospital had some form of medical treatment withheld or withdrawn after they had been designated DNR. This included blood tests, medications, administration of blood products and intravenous fluids, use of a respirator and dialysis equipment, and surgical procedures. Schwartz and Reilly (1986) similarly

found that American AC patients had less aggressive therapy, and had diagnostic evaluations limited after a DNR decision had been made. Lipton (1986) also reported significantly less technological care following a DNR order. These findings reflect the concern that DNR orders will reduce the quality of patient care. Apparently quantity of technical intervention is linked to quality of care.

Not all agree that more technology constitutes better care. Two studies found terminally ill patients, who had a DNR order, still received treatment inappropriately oriented to "cure" (Mumma & Benoliel, 1984-85; Evans & Brody, 1985). As already indicated, it is common for DNR patients to be admitted to the ICU, where aggressive forms of life support are implemented (Lewandowski et al., 1985). DNR patients have also been found to have tube feeding implemented after they had stopped eating or drinking enough to sustain life (Wilson, 1991). Honan et al.'s (1988) survey also found 91.8 percent of American nurses felt the quality of nursing care would not deteriorate after a DNR order was written. Most laypersons, in Honan et al.'s (1988) survey, similarly felt their care would be maintained (97.1%), and 69.2 percent of physicians felt care would not deteriorate. Thom (1988) also found British nurses and physicians felt a "not for CPR" order would not reduce either the medical or nursing care. Technological interventions may not have replaced the "non-technical" interventions that were and have been used to comfort dying persons, since Lewandowski et al. (1985) noted that DNR patients in the ICU required the most nursing care. Technological interventions however appear to have gained greater prominence.

As illustrated in this section, information on the effects of DNR decisions has been limited to the impact of a DNR order on patient care. The effect of a DNR decision on patients and families does not appear to have been investigated. Lack of research and therefore information may reflect the lack of opportunity for patients and families to react to DNR orders. Godkin (1992) found competent patients unaware of DNR orders in their charts. Only two studies appear to have investigated the effect of CPR and life revival on patients. Dougherty (1990) found inpatients, after CPR, were very disturbed by

their CPR experience. Uncertainty, and feelings of loss of control and denial were high during hospitalization. Bedell and Delbanco (1984) investigated whether or not surviving patients, after their hospitalization, would wish to be resuscitated again. One third of the patients indicated that they would not, but unfortunately, no reasons for this preference were reported.

Comparison of Influences for DNR Policies and End-Of-Life Decisions

Only one similar influence, physician involvement, was noted when research-based influences for DNR policies and for end-of-life decisions were compared. Other influences, not supported by research, were found common to both DNR policies and end-of-life decisions. One such influence is the need to make a rational, timely, and appropriate decision. Three infrequently mentioned but corresponding influences include the impact of laws, accreditation requirements, and professional documents and standards. The values, beliefs, and knowledge of patients and their families, physicians and nurses, and health care administrators may also contribute to the variability of DNR policies and end-of-life patient care decisions. In total, six similar influences are apparent when the DNR policy and end-of-life literature is compared.

Type of Health Care Facility

The type of health care facility could potentially influence the development and content of DNR policies, and the end-of-life patient care decisions made there. Major distinctions in the nature of patient care exist between AC and LTC facilities (President's Commission, 1983). Most LTC facilities either have no life supporting equipment or a minimal amount of very basic life supporting technologies (Levinson et al., 1989). LTC facilities may not have CPR trained staff, a factor which can greatly limit resuscitation efforts (Levinson et al., 1987). In contrast, all AC hospitals have CPR trained staff and life supporting technologies. Most larger AC hospitals also have an ICU. Treatment options at these various types of facilities therefore differ significantly.

The mandates of LTC and AC facilities also vary greatly. The mission and philosophy statements of LTC facilities reflect a lack of aggressive technological support (Gregory, 1987; Hiller, 1987) and generally an awareness of death and dying (Wilson, 1992). Supportive or non-curative care of LTC patients is a common philosophical component of LTC mission statements. AC facilities, instead, commonly have a philosophy reflecting a "cure" orientation (Gregory, 1987; Hiller, 1987; Mumma & Benoliel, 1984-85). The President's Commission (1983) similarly deemed AC hospitals to have a "predominant predisposition to prolonging life" (p. 106). AC facilities may need DNR policies to counteract a tendency to aggressively treat all patients.

With primary dispositions to either "cure" or "support", it would not be unusual to discover differences in the policies and the end-of-life patient care provided in LTC and in AC facilities. However, the setting may not influence some aspects of patient care. Bedell and Delbanco (1984) found no difference in the probability that physicians would discuss resuscitation with medical patients in comparison to ICU patients. Mumma and Benoliel's (1984-85) finding that most deaths occur in ICU patients and not medical or surgical patients also makes it obvious that care would differ between these two settings. ICU patients naturally receive more technological support.

Size of Health Care Facility

The size of health care facilities may also be important in whether DNR policies are developed and adhered to, and what end-of-life decisions are made. For example, Brown and Thompson (1979) reported that patients were less likely to be treated for high fevers if they resided in a small (less than 50 bed) LTC facility. Longo et al. (1988a) found that large AC and LTC facilities were significantly more likely to have DNR policies. Miles and Moldow (1984) similarly reported that 89 percent of large AC hospitals (more than 400 beds) had DNR policies, while only 28 percent of small (under 50 beds) AC hospitals did. Levinson et al. (1987) however reported that they found no significant differences, between LTC facilities that were over or under 100 beds in size, in

either the presence of a policy, whether resuscitation had been discussed, or whether no-CPR orders had been written.

Conceptual Framework

A conceptual framework, explaining the proposed relationship between research concepts, was devised for this research study. A conceptual framework is relevant when concepts or variables have been explored in previous research, but no relationships between them have been established (Brink & Wood, 1983). The conceptual framework devised for this study largely emulates General Systems Theory (GST).

GST was initially developed between the years of 1920 to 1954 by von Bertalanffy (Gray & Rizzo, 1969; Putt, 1978; von Bertalanffy, 1968). Since then his theoretical tool has been adapted and used for many different purposes, and by many scientists and disciplines (examples: Berman, 1978; Cavallo, 1982; Gray, Duhl & Rizzo, 1969; Hodgetts & Wortman, 1980; Jenkins, 1978; Putt, 1978). Putt (1978) felt GST constituted a different way of looking at the world. Instead of focusing on specific concepts in isolation, the relationship of these concepts or component parts to each other is important (Boulding, 1968; Putt, 1978). GST's popularity largely grew from its refocusing of science toward wholes and wholeness (Gray, 1969; von Bertalanffy, 1968). An arrangement of interrelated concepts or component parts is deemed to be a "system" (Abbey, 1978; Hall & Fagen, 1968; Klir, 1972). There may be varying degrees of association between these component parts. Berman (1978) felt it was possible for systems to be loosely coupled. Ashby (1972) however summarized GST as "a demand that we treat systems as wholes composed of interrelated parts, between which interaction occurs to a major degree" (p. 95).

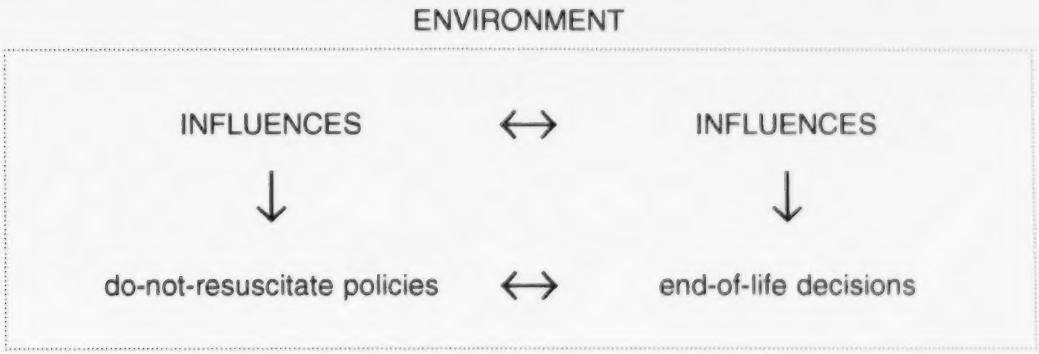
Another major contribution of GST is its focus on the interaction of systems with their environments (Putt, 1978). Systems may be closed or open to environmental influences (Abbey, 1978). Health care facilities, like other social service delivery organizations, are recognized as open systems (Berman, 1978). As such they are affected by federal and provincial laws, national and local accreditation and other standards, societal expectations and needs,

professional values and obligations, ethical influences, and many other influences. Berman (1978) felt public organizations experience turbulence as they respond to their uncertain and uncontrollable exogenous environments. Von Bertalanffy (1967) however felt systems that are open are not in disarray, since they either have a steady state or evolve toward a steady state.

Hiller (1987), like many other health care administrators, recognized that both external and internal forces influence health care organizations. Influences affecting a system may be divided into either micro (individual), meso (organizational or professional), or macro (societal or community) system levels (Aroskar, 1987). Hiller (1987) recognized that these levels are distinct, but are not mutually exclusive of each other. Gregory (1987) also noted the interrelationship of influences in health care organizations, as he related that many interacting factors in health care organizations influence administrative actions. Influences for action in one level may therefore be an influence for actions in another level.

Institutional (meso level) DNR policies may be affected by micro, macro, and other meso level influences. Micro level end-of-life patient care decisions may also be affected by meso, macro, and other micro level influences. GST therefore provides a conceptual link between the concepts, DNR policies and end-of-life decisions, since both concepts occur within the same health care system (see Figure 1). Two concepts, according to GST, occurring within the same system would necessarily have a relationship with each other. Furthermore, both concepts since they are contained within the same system may be subject to corresponding meso, macro, and micro influences which affect the system. Influences affecting the system would then affect DNR policy formation and adherence, and resultant end-of-life care decisions. Some influences which have been reported to affect DNR policy formation are the same influences affecting end-of-life treatment or non-treatment decisions. The proposed study seeks to determine whether there is a relationship between the influences for DNR policies and the influences for end-of-life decisions.

Figure 1. Schematic representation of the conceptual framework.



Significance of Study

At this point in time there is only minimal knowledge of what potentially may influence the development of DNR policies and end-of-life patient care decisions. Learning what influences DNR policy formation and end-of-life decisions are key considerations if life support is to be optimized. This study is significant for seven additional reasons.

1. The findings of this study are important for Canadians, since there has been little research undertaken in Canada on life support. This has occurred despite growing unease with life support practices. Much of this unease is based on American legal rulings, litigiousness, and federal and state policies developed to manage this life support dilemma. Publications arising from this study may focus attention on life support, and thus spur other Canadians to conduct research in this area.
2. An improved understanding of the administrative approach, DNR policies, to life support dilemmas is gained through this study. This includes information on the extent of DNR policies in Alberta AC and LTC facilities, the content of DNR policies, when they were derived, and what professional and other groups were involved in their development.

3. Policy adherence is only occasionally reported in the research literature. No previous Canadian studies, reporting on policy adherence, have been found. With DNR policies being designed to aid end-of-life decision-making, it would be helpful to learn if these policies guide decision-making. This information is extremely relevant for health care administrators and policy makers, along with physician, nurse, and other groups.
4. Another significance pertains to the concern, primarily reported in the U.S.A., over whether a DNR order reduces the quality and quantity of care provided to patients. There does not appear to have been an investigation in Canada of the effect of DNR orders on patient care. Information on the effect of a DNR decision could be highly influential for Canadian health care administrators and policy makers, along with physicians, nurses, and other groups.
5. This proposed research study also gathers baseline data for comparison with data from a future replication of this study. The replication is planned to occur approximately one year after ATD legislation is implemented in Alberta. The effect of ATD legislation upon DNR policies and end-of-life care can be evaluated through this comparison. This information will be extremely relevant to lawyers, as well as to other groups.
6. Despite many articles and some research papers which pertain to DNR policies, there does not appear to have been an investigation of the influences for DNR policies. This oversight is significant and rectifying it is important for health care administrators and others who are attempting to improve life support practices.
7. In addition, there does not appear to have ever been a comparison of the influences for DNR policies and the influences for end-of-life decisions. Only Younger (1987), an experienced ethicist, appears to be aware of the possibility of a diversity of influences. He suggests that different values may affect each of the many treatment decisions made for a patient at the end-of-life. He feels that different values and therefore decisions make "the overall pattern of treatment or nontreatment seem confused or

inconsistent" (Younger, 1987, p. 31). Therefore, this research study provides significant and unique data to those involved in the quandary produced by the availability of many life supporting interventions. Data from this study may be used to better inform people of the variables affecting the entire spectrum of end-of-life decision-making. The findings of this study may be beneficial for stimulating thoughtful change in macro, meso, and micro level attempts to optimize the use of life supports.

Chapter III
Methodology

Overview of Design

This study was designed with three phases.

1. A mail questionnaire survey of DNR policies, and the influences for those policies, in all accredited Alberta AC and LTC facilities.

2. A review of patient care records of all recently deceased patients in selected representative health care facilities to obtain information on end-of-life decisions and the influences for those decisions.

3. Interviews of nurses and physicians, who cared for selected deceased patients, regarding influences for end-of-life decisions.

These phases were carried out, following attainment of ethical approval on October 8, 1992, from the Department of Educational Administration, Faculty of Education at the University of Alberta, and with formal approval from each of the facilities in which data collection occurred. A further discussion of ethical considerations follows a description of the setting, target populations, procedures for each phase, and samples for each phase; instruments, and considerations of the validity and reliability of measurement. A data analysis overview completes this chapter.

The Setting, Target Populations, Procedures, and Samples

The setting for the study was the province of Alberta. The target populations, procedures, and samples varied for each phase of the study.

Phase one, DNR policies in Alberta health care facilities. Information about the presence of and also influences for DNR policies in all accredited Alberta AC and LTC (N=175) facilities was sought. One SNA in each facility was asked to provide this information. Limiting the setting to Alberta was a key decision. Each province has a unique health care system with different laws and regulations. Widely divergent influences for DNR policies could potentially be found across Canada. An awareness of these potential differences is borne out

by Singer's finding that 17 to 79 percent of AC hospitals in provinces across Canada reported DNR policies (personal communication, June 23, 1992). The possibility of finding a unique set of influences for DNR policies and end-of-life decisions was therefore increased by confining the study to Alberta. Another factor in this decision was the familiarity of the principal investigator (PI) with the health care system of Alberta. Furthermore, Alberta is likely to have ATD legislation implemented in the near future, which will allow examination of the role of legislation on DNR policies and end-of-life treatment decisions.

Another key decision was the targeting of SNAs for the provision of policy information. These highly responsible individuals are senior administrators in their health care facility, and, as such, have access to policy and procedure manuals. They are also likely to have been involved in DNR policy development or, if not, are privy to information on the formation of these policies. Furthermore, sending out the questionnaires in late October, 1992 to SNAs was felt to be an appropriate time, since few would be expected to be on holiday.

A third key decision was the limitation of surveys to only those facilities that were currently accredited by the Canadian Council of Health Facilities (1992). Accreditation standards denote a minimum accepted level of performance, and lack of accreditation may mean this minimum level has not been attained. Approximately one half of AC hospitals in Alberta are accredited (Canadian Hospital Association, 1991). In comparison, only about one quarter of LTC facilities in Alberta are accredited (Canadian Hospital Association, 1990). Many non-accredited LTC facilities are small lodges with no life supporting technology. Limiting the target population to accredited facilities improves the homogeneity of the sample, and removes the possibility of extraneous findings from a less homogenous sample.

The last consideration was the inclusion of both AC and LTC facilities in the target population. Eighty-five percent of Canadians currently die in health care facilities (personal communication, CBC radio, September 22, 1992). Most Albertans, then, can be expected to die in either an AC or LTC facility. Professional and organizational responses to the need for end-of-life decisions are therefore important in both AC and LTC facilities.

The addresses of all accredited AC and LTC facilities in Alberta (N=175), and the titles of the SNAs in each facility were obtained from the 1991-92 Canadian Hospital and Long-Term Care Directories (Canadian Hospital Association, 1990; 1991). Every identified SNA was sent, in mid October of 1992, a questionnaire surveying DNR policies (Appendix A) and a cover letter informing them of the study and requesting their participation (Appendix B). The questionnaires were anonymous, but were coded to identify non-responding facilities.

Initially 65% of the questionnaires (n=114) were returned by the one month deadline. In late November, 1992 non-responders were sent another questionnaire and a reminder letter (see Appendix C) requesting their participation in the study. By the second deadline date of December 30, 1992 81.7 percent of the questionnaires (n=143) were obtained. Eight questionnaires were then discarded because facilities reported they were no longer accredited. A total of 135 questionnaires were retained for analysis (80.9%). Using the Canadian Hospital Association (1990; 1991) directories, which defines health care facilities as being either AC or LTC, responses were obtained from 70 of the 83 AC hospitals (84.3%), and 65 of the 84 LTC facilities (77.4%). SNAs, however, reported differently; 49 responses were from LTC facilities (36.3% of sample), 45 were from AC facilities (33.3% of sample), and 41 were from facilities reported to be "other" than primarily an AC or a LTC facility (30.4%). Surveyed facilities could also be described as either small (n=35, 25.9% of sample), medium-sized facilities (n=74, 54.8%), or large facilities (n=25, 18.5%). There was one mainly ambulatory care facility (.7%) that was also surveyed and responded. Facilities could be further divided into those reported as having (n=47, 34.8%), or not having (n=88, 65.2%) intensive care beds and the associated technologies.

Facilities that did not return a questionnaire were similar to the facilities from which a questionnaire was returned. In total, questionnaires were not returned from 24.4 percent of the AC and 22.6 percent of the LTC facilities. Non-returns also represented: 34 percent of small facilities (the small LTC facility non-return rate was higher), 17 percent of medium facilities (equally

distributed between medium sized LTC and AC facilities), and 23.3 percent of large facilities (the large AC facility non-return rate was higher).

Phase two, chart reviews. The second target population comprised all inpatients who receive end-of-life care in accredited AC and LTC facilities in Alberta. Furthermore, this care is provided in one of three common types of health care facilities; LTC facilities, AC hospitals with intensive care beds, or AC hospitals that do not have intensive care beds. These facilities differ in availability of life supporting technologies, and may differ in organizational mandate as well as approaches to end-of-life patient care.

The sample comprised all inpatients who died in select health care facilities in the six-month interval (June to December, 1992) immediately prior to data collection. Facilities were selected on the basis of their representativeness of the three types of health care facilities (LTC, AC without ICU, and AC hospital with ICU). Due to the limited number of deaths (n=6) at one small AC facility that did not have an ICU, data was also gathered at a second similar facility. To make comparisons between patients more valid, only accredited facilities were selected, and all four must have had a DNR policy that had been approved for at least six months before data collection. The four facilities were also selected on the basis of their convenience to the city of Edmonton. These facilities were accessible for ongoing data collection.

The sampling for this second phase of the study was limited to adults (18 years of age or older), who had been patients for at least one week before their deaths. Patients who died before residing less than a week in a health care facility were excluded from this sample, since the influences for their end-of-life decisions may be vastly different from in-patient decision influences. Furthermore, in-patients, who had been in hospital for at least one week, had more care provided by AC and LTC staff. More information from nurses and physicians on the influences for end-of-life decisions could then be expected. In addition, only the most recent deceased patients' charts in each facility were reviewed to facilitate physician and nurse recall, hence the decision to only

review the charts of those patients who had died within the previous six month period.

Following the selection of representative institutions, administrative and ethics approval to conduct research in each of these facilities was obtained. A copy of each facility's DNR policy was also obtained. The patient care records for all recently deceased patients were then reviewed using a simple data collection sheet (Appendix D). Data collection for this phase of the study occurred entirely within the month of December, 1992.

Retrospective chart reviews were therefore undertaken. Alberta health care facilities are required to keep select parts of patient care records for ten years following the death of a patient. This requirement standardized, and made possible, the data collection from charts. A review of patient care records of recently deceased patients provided information on life supporting interventions used during the end-of-life period, and the influences for those care decisions. Adherence to the facilities DNR policy was also determined during these reviews.

Six patient charts were reviewed in the first small AC (AC/S) facility, 13 from the second AC/S facility, 40 from the LTC facility, and 78 from the large AC facility that had ICU beds and technologies (AC/ICU). The total sample consisted of 137 patients. The patients ranged in age from 19 to 97 years; with an average age of 70.9. A significant difference between the mean ages of the three groups of patients was found (F[raw scores]=20.5503, p=.0000; χ^2[grouped scores]=40.86849, df=8, p=.00000). The AC/ICU hospital group averaged 63.5 years of age, the AC/S group averaged 74.4 years of age, and the LTC group averaged 83.55 years of age. These patients were relatively equal however in gender distribution; 67 were male (48.9%) and 70 were female (51.1%). No significant difference between the patient's gender and type of health care facility where they died was observed (χ^2=.41264, df=2, p=.22543). Female patients averaging 76.1 years of age were significantly older then male patients averaging 65.4 years of age (χ^2(grouped ages)=14.66588, df=4, p=.00545; t test (raw scores)=-3.53, df=135, two-tailed p=.001).

Phase three, interviews. The target population for the third phase of the study was 30 deceased inpatients; 10 from each of the three types of health care facilities where data had already been retrospectively collected from 137 patient charts. Patient cases were randomly selected from all available within that facility. If there was not a written DNR (no-CPR) order in the chart, then an alternate randomly selected patient was substituted. Of all 137 patients, only 11 (8%) did not have a DNR order in their charts at the time of their death. There was a borderline significant relationship between the gender of these 11 patients and the absence of a DNR order (χ^2=2.71627, df=1, p=.09933). There was no relationship between the age of patients and absence of a DNR order (χ^2=2.09989, df=4, p=.71739; F[raw scores]=.9248, p=.3380).

The 30 randomly selected patients were compared and found representative of the larger sample. Patients were similar in age (71.6 years of age in the AC/S facilities, 86.2 years of age in the LTC, and 63 years of age in the AC/ICU hospital) and gender (15 males and 15 females) to the previous sample of 137 patients. Some variation occurred by chance in the average length of stay of these 30 patients (23.1 days compared to 21.8 days on average for all patients in the AC/S facilities, 1945.1 days compared to 936.83 days on average in the LTC, and 19.8 days compared to 23.1 days on average in the AC/ICU).

The sampling for this phase of the study further consisted of thirty pairs of one nurse and one physician per randomly selected patient. Ten pairs of health care professionals were sought from the large AC/ICU facility, ten pairs from the LTC facility, and five pairs from each of the two AC/S facilities. These health care professionals were expected to be knowledgeable of the influences for end-of-life decisions for the selected patient. Nurses and physicians were therefore required to recall details about patient care. If at least one nurse and one physician per patient case were not available, willing to participate, or knowledgeable of the patient's treatment or non-treatment influences, and no satisfactory substitute could not found, then another patient case was randomly selected. Procedures to interview one nurse and physician for that substituted case were again followed.

Before the interview and following the identification of appropriate nurses and physicians, an information letter and consent form (see Appendices E and F) were sent to each possible participant. The letter and consent form advised nurses and physicians of the study and asked them to participate in an interview designed to identify influences for end-of-life patient care decisions. All interviews were conducted via the telephone. Immediately prior to the actual interviews, the PI used a checklist to ensure that participants were fully informed of the purpose of the study (Appendix G). An interview data collection sheet was then used to record interview data (Appendix H).

Most initially identified physicians and nurses were interviewed. However, three physicians refused to be interviewed and one physician was unavailable, necessitating four additional random selections of patients. In another instance a physician could not recall influences, so another patient was randomly selected. All initially selected nurses were interviewed, with one exception. One nurse had moved and was unavailable for data collection, but another nurse was found to be a satisfactory substitute for that patient. Nurses could freely recall influences. Five physicians in the AC/ICU hospital, however, recalled influences only after rereading the chart. One physician in the LTC facility and one physician in the second small AC facility similarly recalled influences only after rereading the chart; which raised concerns over the accuracy of physician recall. Concerns were offset by the expressed need of physicians to be accurate in their responses. In total, 30 nurses and 30 physicians were surveyed over a three month period (December 15, 1992 to February 23, 1993).

Only general practitioners and specialists were interviewed. In the large AC/ICU facility all physicians were specialists; in comparison to general practitioners at the smaller AC facilities and LTC facility. Apparently only fully qualified physicians (not physicians acting in a student capacity) signed DNR orders and were thus instrumental in end-of-life care decisions. In no cases were student physicians interviewed, although interns and residents commonly had ordered diagnostic tests and treatments for patients.

In the large AC/ICU facility, nursing managers were selected to be interviewed. Nursing managers are responsible for ongoing patient care on their respective unit. Managers generally work five day shifts during the week, and are thus able to discuss end-of-life care with physicians who make patient rounds during these day shifts. Nurse managers were found to have been commonly involved in end-of-life care decisions. In the two instances where nurse managers were not personally involved in end-of-life decisions, these nurses were still aware of the influences for end-of-life decisions. In contrast, only four nursing managers in total at the AC/S and LTC facilities were interviewed. Sixteen staff nurses, in these facilities, instead were interviewed, as they had been extensively involved in ongoing patient care.

All interviewed nurses and physicians were knowledgeable of the patient and the end-of-life care provided. Great variation in the amount of discussion between the PI and individual nurses or physicians occurred, however. Nurses tended to be talkative, while physicians tended to be less verbose.

Instruments

Phase one. A mail survey questionnaire, with mainly forced choice and few open ended questions, was designed by the PI in early 1992 (Appendix A). This instrument gathered data on the extent, content, and influences for DNR policies.

Phase two. A one page data collection sheet was also designed by the PI for recording data gleaned from patient care record reviews (Appendix D). The existence or absence of written DNR (no-CPR) orders, the types of potentially life supporting technologies used at the end-of-life, and influences for these care decisions were sought.

Phase three. A one page interview data collection sheet was then designed by the PI (Appendix H). This instrument was used to record recalled influences for end-of-life treatment and non-treatment decisions.

Validity and Reliability of Measurement

Validity. Face, content, and concurrent measures, were employed to enhance the validity of measurement. The validity of the three tools and the data collection ability of the principal investigator were all considered. A summary of these measures follows. Beyond internal validity of measurement, the external validity of the research findings was also considered. In particular, the external validity or generalizability (Moser & Kalton, 1971) of data was considered in the decision to survey all accredited AC and LTC facilities in Alberta. A high return rate and the similarity of non-responding facilities to responding facilities enhances the validity of findings.

The mail questionnaire was developed after a survey of life support policies in all local AC and LTC facilities (n=19) had been undertaken in February and March of 1992. The questionnaire questions and detractors for forced choice questions were devised using findings from, and terminology within, the policy and procedure manuals. A comparison of these devised questions with Enderlin and Wilhite's (1991) DNR survey questionnaire was also undertaken for furthering content and face validity. The drafted questionnaire and a cover letter (based on the Faculty of Nursing Ethics Committee example cover letter) were then distributed to all 19 Directors of Nursing in the AC and LTC facilities where the DNR policies had been initially surveyed. All 19 had verbally agreed to complete the questionnaire, and evaluate the questionnaire and cover letter (see Appendix I for Evaluation of Survey Questionnaire tool). Thirteen completed questionnaires and reviewed cover letters were returned by August 1, 1992. Suggestions on these documents led to some minor wording changes to the questionnaire and improved instructions. Furthermore, no discrepancies were noted between the answers given by the Directors of Nursing on the questionnaires, and the data that had been obtained by the PI during the previous survey of policy and procedure manuals. This step further enhanced face and content validity of the questionnaire.

It was at this stage of tool development that the PI learned of other surveys of DNR policies in Canadian AC hospitals and in Canadian LTC facilities. The survey questionnaires, developed and circulated by Singer, were obtained. His

two studies were found to be similar in intent to the PI's. As a result of this similarity, the original exploratory-descriptive focus of the PI's study was changed to the current descriptive-comparative focus. Ten questions consequently were removed, and three questions were added to the questionnaire (regarding the influences for DNR policies, who had been involved in developing the DNR policy, and if the respondent had been personally involved in the development of the DNR policy). The question seeking a description of DNR policy influences was specifically designed to be open ended to improve the validity of responses as suggested by Oppenheim (1966). Respondents could take time to reflect on their answer and seek input from other individuals in the facility if required. Ten available Directors of Nursing, again in the greater Edmonton area, were then telephone interviewed regarding the wording and intent of these three questions. All ten related they could understand and answer the three questions. Their answers about DNR policy influences were based on their recall of influences and were not subjective opinions of possible influences, which also enhanced the validity of the tool (Fowler, 1984; Sudman & Bradburn, 1986). Finally, the reading level of the questionnaire and cover letter were both established to be at a grade 8 (Flesch-Kincaid) level using a computer program designed for such a purpose (Grammatik, 1991). Face and content validity were addressed through these questionnaire development stages.

As indicated, the Patient Care Record Data Collection Tool (Appendix D) and the Interview Data Collection Tool (Appendix H) were also developed by the PI. These tools were simply designed to ensure that (a) all required demographic data and the documented influences for specific end-of-life treatment decisions would be recorded and (b) all recalled influences and other information would be recorded accurately.

Five nursing managers, who were currently employed in a LTC facility that has a DNR policy, were approached and agreed to help with a pilot test of the study. These managers individually completed the questionnaire and then were asked privately if the questions were understandable. All replied they were. Their answers demonstrated that they had understood the questions and

could answer them, although it was apparent that they had not been involved in the development of the facility's DNR policy. Their responses about the possible influences for DNR policies, however, reflected what had been previously reported in the literature and what had been reported by the ten Directors of Nursing. Face and content validity was again established through this step.

The Patient Care Record Data Collection tool was also used to collect data from the charts of five hospitalized DNR patients. In this pilot test, it was discovered that there were no influences documented in any of the Doctors Orders Sheets on the five charts. A few influences instead were written in the Physician's Progress notes. Some influences were also charted in the Nurses Notes. No changes were made to the Instrument following this pre-test since it was felt to be valid in its design and focus. From this pilot test, it was anticipated that documentation, regarding the influences for DNR decisions, would be limited. It would be important to interview nurses and physicians to obtain information on the influences for end-of-life treatment and non-treatment decisions.

The Interview Data Collection Tool was also pre-tested for validity through two mechanisms. The five nursing managers mentioned above, and then five physicians who had cared for the five selected patients, were interviewed privately regarding what they felt had been the influences for the DNR order that was found on the five identified patients' charts. All ten health care professionals could remember one or more influences, even over a six month period. Both nurses and physicians were asked if they had understood the question "What influenced the DNR decision?". All reported they had understood the question, and all answers reflected that they had understood the question. When their answers were read back to them, they agreed that the answers were correctly recorded, which demonstrates both reliability and validity of the PI's data collection method. Their answers reflected literature findings, which again establishes validity. The reading level of the Introductory letter for nurses and physicians, which explained the study, was also established to be at a grade five level. This letter is believed to have improved

the validity of obtained data since nurses and physicians had an opportunity to reflect on what factors had influenced end-of-life care decisions before the interview took place (Oppenheim, 1966).

One additional aspect of validity, that of the data manipulation, was addressed. Specifically, the categories developed through content analysis by the PI (for DNR policy influences and end-of-life treatment decision influences) were compared to the categories of influences that had been noted in the previous literature review. Similarities between these two were observed to exist. A second person, versed in content analysis, then verified that the devised categories were mutually exclusive and that the data had been correctly classified into each category. Furthermore, the accuracy of data in the computer files was verified by both the PI and the research assistant before and also during the data analysis.

Reliability. Aspects of reliability, or the means of increasing confidence in the consistency, stability, and repeatability of the three tools, were also addressed. Reliability of data analysis was also addressed. In particular, the repeated tests/retests of the questionnaire, as indicated above, addressed the stability of this instrument. First, the data regarding DNR policies was found identical between the PI's initial survey and the Directors of Nursing's survey three months later. Second, nursing managers were surveyed over a two day period of data collection in August, 1992. This survey also established the continuity of responses.

Reliability was also addressed by the preferential use of a mail questionnaire to obtain data on influences for DNR policies from SNAs. Nurses and other individuals at this organizational level are required to be knowledgeable of facility policies. A mail questionnaire allowed time for reflection and discussions with other persons should the SNAs have felt a need to validate questionnaire answers. The order of questions, length of the questionnaire, and instructions to participants also received considerable attention, as suggested by Sudman and Bradburn (1986).

A self reliability check was used by the PI to ensure that appropriate documentation of information obtained during the pretest of the Patient Care Record Review Data Collection Instrument had occurred. After each chart had been reviewed in the pilot test, the PI reviewed the obtained data for completeness with the appropriate nursing manager. The five nursing managers felt the recorded data was accurate (100% agreement). A test-retest of the Interview Data Collection Instrument also addressed the stability of this instrument. The PI gained experience with interviewing each of the nursing managers and physicians, and thus gained familiarity with recording their answers. Furthermore, at the end of each nurse manager interview the PI asked the nurse to validate that the recorded influences for both DNR policies and end-of-life decisions correctly reflected what that nurse had meant to say. In addition, the five nursing managers were telephone interviewed one day after their interview and the recorded influences were again validated. Influences for end-of-life patient care decisions on that day did not vary from the influences recorded on the initial interview (100% agreement). Influences for end-of-life treatment and non-treatment decisions reflected historical facts for nurses.

Fowler (1984) reports that memory and knowledge problems affect the reliability of data obtained through interviews. However, it was found that the 10 initially surveyed nurses and physicians in the pilot test could remember decisions that had occurred up to and exceeding a six month period. End-of-life treatment decisions did not appear to be routine for either nurses or for physicians. To further address reliability issues, if a nurse or physician selected for the study could not recall influences for patient care decisions then substitution was planned (and did occur in one case).

The PI gathered data reflecting a six month period of time to further enhance stability of influences. Simultaneous environmental influences would be affecting SNAs completing the questionnaire and the health care professionals involved in end-of-life patient care. Any differences in influences for DNR policies and for end-of-life treatment decisions should then reflect a true difference in these influences. Data collection was also compressed in time to enhance the reliability of obtained data. Finally, it should be mentioned

that only the PI gathered data during the patient care record reviews and interviews, which is another measure of reliability (Oppenheim, 1966).

Ethical Considerations

The following ethical considerations were relevant to this study.

Explaining the purpose and nature of the research study to participants. SNAs were informed of the purpose and nature of the research study in a cover letter (Appendix B). This letter also explained that they could refuse to participate in the study without prejudice. This cover letter was previewed for clarity by 13 Directors of Nursing in Edmonton, during a pretest of the mail questionnaire.

Nurses and physicians who were identified for data collection were sent an introductory letter (see Appendix E), informing them of the purpose and nature of the study. This letter also informed them that they would be asked to participate in a verbal interview, that they could refuse to be interviewed when they were contacted by the PI, and that they could opt out later. Nurses and physicians were, simultaneously, sent two copies of a consent form, requesting their participation in the study (see Appendix F). One copy was to be signed and returned via a stamped envelope to the PI and one was to be kept by the nurse or physician. Before the interview, the PI followed the Prerequisite Discussion Guidelines (Appendix G) to ensure that the nurses and physicians understood the nature and purpose of the study. Any questions and other concerns were answered by the PI, and a verbal consent was also obtained from each subject before their interview.

Obtaining informed consent from participants. SNAs either consented to participate in the study through completing and returning the mail questionnaire, or they did not complete and return the questionnaire. Nurses and physicians similarly agreed to participate in the study and were interviewed by the PI, or they did not agree to participate in the study and were not interviewed. As indicated, written and verbal consents were obtained from

nurses and physicians before their respective interview. The four facilities provided necessary administrative and ethical appraisal for data to be collected from patient care records, since deceased patients could not give consent for their charts to be reviewed.

Providing for the right to opt out of the research study. SNAs who wished to opt out were informed that they could have their questionnaire removed from the data set (which had been made possible by the numeric identification or coding of questionnaires). The cover letter explained that SNAs wishing to opt out may contact the PI. The address and telephone number of the PI was included on the cover letter primarily for this purpose. Nurses and physicians also could opt out any time, and they were so informed in the introductory letter and again verbally by the PI. They could refuse to be interviewed and thus opt out in this fashion.

Addressing anonymity and confidentiality issues. Anonymity and confidentiality were maintained through the following safeguards: (a) mail questionnaires were only coded by a number and did not have the name of the facility or the SNA on them, (b) the coded copies of the 1990 and 1991 Canadian Hospital Directories are kept in a locked drawer only accessible to the PI, (c) the names of patients, nurses and physicians, are also kept in a locked drawer only accessible to the PI, (d) seven years after the study is completed all of the completed instruments and questionnaires will be destroyed by a shredding method, according to University policy, (e) all data will be reported as grouped data only, and (f) the names of people or facilities will never be used in any reports, discussions, or publications.

The SNAs, nurses and physicians were informed that safeguards for confidentiality and anonymity were being taken. The cover letter to SNAs and the introductory letter to nurses and physicians emphasized that all responses would be anonymous, no names of persons or facilities would ever be used in any reports or publications, and any information that they gave to the PI would not be disclosed to any other person.

Avoiding threat or harm to participants or to others. There was no possibility of physical harm to any participant due to the (non-physical) nature of this study. SNAs, nurses, and physicians choose to participate in the study, which should have reduced any emotional unease or intellectual concern over disclosure of information. In particular, no physical harm can occur to patients who are deceased. Relatives were not aware that a patient care record review had been undertaken, and therefore could not be harmed or inconvenienced in any way. Finally, physicians who did not wish to be interviewed refused to be interviewed. It is unfortunate that the PI interviewed nurses and physicians regarding patients who had died. Interviews, although not intending to elicit feelings or emotions, may have done so since health care professionals are not insensitive to death and dying. Unresolved grief over the deaths, however, was not discovered on interviewing. Furthermore, in only a few isolated instances was there unease over the life supporting interventions that had been used at the end-of-life.

Limitations

Five limitations of the study are apparent.

1. Not all questionnaires were returned. The data set is therefore incomplete. This limitation is minimized by the high return rate (81.7%) and the fairly equal distribution of returned questionnaires (based on size and type of facility).
2. A convenience sample of health care facilities was employed for both the chart reviews and the interviews. The limitation of reduced generalizability of data was offset by the careful selection of facilities that represented the three types of facilities.
3. Two small AC hospitals, instead of the one intended, were used as sites to gather data. These two facilities were similar in size and other characteristics; as both had a long-standing DNR policy and neither had ICU technologies nor beds. It was expected that end-of-life care would then be similar, but differences in care or in the influences for that care may have occurred.

4. Only 30 patient cases were selected for additional data collection purposes. This number of patients may not be entirely representative of all 137 patients who died in the designated six month period. This limitation occurred as a consequence of interviewing being a lengthy task to arrange and accomplish. The retrospective nature of interviewing and the fact that the interviews were only augmenting charted information further substantiated this design decision however.

Assumptions

Three assumptions were made.

1. SNAs were the most appropriate individual in the health care facilities to send mail questionnaires to.
2. All participants would share information accurately and fully.
3. The data collection tools and methods would collect valid and reliable data.

Data Analysis Overview

The findings from the study were analyzed largely through quantitative statistical methods available through SPSS (SPSS for Windows, Release 5.0.1, October 9, 1992). Prior to computer analysis, content analysis of influences was undertaken. Following this, demographic findings were configured. Cross-tabulations of data, reflecting the frequency and percentage of responses for variables were devised. Non-parametric and parametric statistical testing was then undertaken to describe relationships between variables.

The test chosen to describe relationships was dependent on the level of measurement of the variables, as indicated in the SPSS manual (Nie et al., 1975). The level of significance was set at .10, as was indicated by Kleinbaum and Kupper (1978) to represent the upper level of borderline significance. The type of facility (nominal level data) and size of facility (grouped to become ordinal level data) commonly comprised the independent variables. Dependant variables included the presence or absence of a DNR policy (nominal level data), and the influences for DNR policy and end-of-life treatment or non-treatment decisions (nominal level data). The required statistical test for determining

independence of samples, when independent and dependent variables both comprise nominal data, is the Pearson chi-square test for association, or the Fisher's exact test if a small number of subjects (usually under 30) is present (Bland, 1987; Pilcher, 1990; Nie et al., 1975). Bivariate data analysis methods were chosen over multivariate analysis methods since most dependent variables were nominal in level.

In addition to specific tests chosen for their appropriateness based on the level of measurement, additional parametric and non-parametric tests were used to further investigate and substantiate the relationships between variables (Nie et al., 1975). While use of these additional tests violates their intended assumptions, the robustness of the tests has contributed to the common-place nature of this practice (Nie et al., 1975). In the few instances where results differed between two tests of the same relationship, the test that met the criterion of level of measurement was selectively used and will be reported in subsequent chapters. It should be stressed however, that in almost every instance the additional tests confirmed original findings. This additional step then became a reliability check of the data analysis results.

Chapter IV
Results

Overview

As indicated, the purpose of this study was to compare the influences from which DNR policies were derived to the influences affecting end-of-life treatment and non-treatment decisions. End-of-life decisions were differentiated into those regarding the no-CPR decision, and the decision or decisions to implement potentially life-sustaining technologies at the end-of-life. This differentiation occurred after the influences for end-of-life technology decisions were noted by the PI to be dissimilar to those for no-CPR decisions. Eight specific sub-questions provided information for this purpose. This chapter has been organized according to these eight sub-questions.

Question One. DNR Policy Influences

As a prerequisite to reporting on DNR policy influences, the prevalence, context for, and content of DNR policies in surveyed Alberta health care facilities will be reported. Of all 135 facilities, 98 were reported to have a DNR policy (72.6%), 12 were currently drafting one (8.9%), and 16 had an informal policy (11.9%). Only 9 did not have a DNR policy (6.7%). In total, SNAs in 37 health care facilities (27.4%) reported that their facility did not have a current DNR policy. DNR policies were developed between the years of 1984 and 1992 (inclusive). Slightly more than one half (53.8%) of the policies were written in the 1990s, with more policies being written in 1991 (n=23, 25.3%) than any other year (mode). Neither the type of facility reported by the SNAs (χ^2=.30398, df=2, p=.85900), nor the presence of ICU technologies were associated with DNR policies (χ^2=.12747, df=1, p=.72107). The size of facility was significant (χ^2=5.81231, df=2, p=.05469) however. Most large health care facilities reported having a DNR policy (n=23, 92.0%), in comparison to small (n=24, 68.6%) or medium sized (n=51, 68.0%) facilities.

Policies were developed in facilities that commonly did not refer to terminal patient care in their organizational mission statements (n=52, 53% of 98 facilities compared to n=40, 40.8% that did). Organizational nursing philosophy statements referred more often to terminal patient care (n=51, 52.0% of 98 facilities compared to n=33, 33.7% that did not).

DNR policies contained an array of directives (see Table 1). The most commonly reported directives (in order of prevalence) were: the discussion with patient and/or family about the DNR decision must be recorded in the patient's chart (n=83, representing 84.7% of the 98 facilities with a DNR policy), a physician is required to write the DNR order in the patient's chart (n=81, 82.7%), the patient or patient representatives can refuse life supporting treatments (n=65, 66.3%), the DNR decision is to be based on specified clinical patient criteria (n=60, 61.2%), and the patient or patient representatives can refuse to accept a DNR decision (n=60, 61.2%).

Furthermore, as reported by SNAs, the vast majority of policies were designed for competent patients to be the principal decision-maker (n=86, 87.8% of 98 respondents). The patient's primary physician, family members, significant others, and one or more nurses could also potentially be involved in the DNR decision according to the majority of DNR policies (see Table 2). In the event of patient incompetence, a patient representative (n=33, 33.7% of 98 respondents with DNR policies) was the most commonly designated person to made the DNR decision according to DNR policies, with the primary physician being the next most commonly designated person (n=15, 15.3%), and lastly the patient (see Table 3), based on their previously verbal or written preferences (n=10, 10.2%). However, 54.1 percent (n=53) of DNR decisions were supposed to be based on an unconscious patient's previously verbalized preferences or wishes, and 51.0 percent (n=50) of DNR decisions were also supposed to be based on previously written patient preferences (such as ATDs). Numerous other persons, furthermore, may be involved in decision-making for incompetent patients.

Table 1

Directives in DNR Policies Reported by Accredited Acute Care and Long-Term Care Facilities in Alberta

	Directive	n	percentage
1.	discussion is recorded in patient chart	83	84.7%
2.	physician must write DNR order in chart	81	82.7%
3.	patient or representative can refuse life supporting treatment	65	66.3%
4.	clinical patient criteria for DNR decision	60	61.2%
5.	patient or representative can refuse DNR order	60	61.2%
6.	educational or informational requirements of patient or representative	46	46.9%
7.	DNR decision is repeated on each admission	45	45.9%
8.	DNR decision is reviewed on a regular basis	45	45.9%
9.	when DNR decision-making is to occur	33	33.7%
10.	DNR order is reviewed periodically	32	32.7%
11.	use living will to learn of treatment preferences	23	23.5%
12.	only physician can rescind/change DNR order to allow resuscitation to occur	21	21.4%
13.	other	18	18.4%
14.	use living will to learn who may be a surrogate decision-maker	10	5.3%
15.	use living will to learn who should not be a surrogate decision-maker	4	4.1%

Note. Maximum score = 98.

Table 2

Principal Decision-Maker if Patient Competent, and Other Persons Who May Be Involved in Decision, as Indicated by DNR Policies

Primary or main decision-maker	n	percentage
1. competent patient	86	87.8%
2. patient's primary physician	10	10.2%
3. other(s)	0	0.0%

Note. Maximum score = 98, 2 facilities did not reply.

Persons who may also be involved in decision	n	percentage
1. primary physician	92	93.9%
2. competent patient	90	91.8%
3. family member(s)	86	87.8%
4. significant other(s)	60	61.2%
5. nurse(s)	50	51.0%
6. member of the clergy	42	42.9%
7. multidisciplinary team	39	39.8%
8. other persons	13	13.3%
9. another physician	11	11.2%
10. Ethics Committee	11	11.2%

Note. Maximum score = 98.

Table 3

Principal Decision-Maker if Patient Incompetent, and Other Persons Who May Be Involved in Decision, as Indicated by DNR Policies

Primary or main decision-maker	n	percentage
1. another person	33	33.7%
2. patient's primary physician	15	15.3%
3. patient (previous verbal or written preferences)	10	10.2%

Note. Maximum score = 98, 40 facilities did not reply.

Persons who may also be involved in decision	n	percentage
1. family member(s)	90	91.8%
2. primary physician	80	81.6%
3. legal guardian	73	74.5%
4. significant other(s)	63	64.3%
5. nurse(s)	57	58.2%
6. public guardian	54	55.1%
7. patient, via previous verbal requests	53	54.1%
8. patient, via previous written instructions	50	51.0%
9. multidisciplinary team	43	43.9%
10. another physician	38	38.8%
11. patient, previous verbal refusal of treatment	37	37.8%
12. member of the clergy	36	36.7%
13. patient, via current behaviours of treatment refusal	25	25.5%
14. Ethics Committee	17	17.3%
15. other person(s)	5	5.1%

Note. Maximum score = 98.

Finally, almost one half of the DNR policies (n=46, 46.9%) were not limited to CPR, but would also guide decision-making for a wide array of life-supporting interventions and technologies (see Table 4). These broadly focused DNR policies were developed between the years of 1984 to 1992. Most of these policies were written in 1991 and 1992 (60.9%), with more broad policies being written in 1991 (n=17, 37.0%) than any other year (representing the mode).

Many different influences for DNR policies were reported, and it was common for SNAs to report that there had been more than one influence for their facility's DNR policy. Five categories of DNR policy influences were developed (see Table 5) when open ended responses from SNAs were classified (listed in order of prevalence): (a) improving the process of end-of-life decision-making, including the appropriate timing of the decision (n=62, representing 63.3% of the 98 facilities with a DNR policy), (b) ensuring the right of patients to be involved in decision-making (n=47, 48.0%), (c) facilitating decisions reflecting professional concerns (notably those relating to life prolongation) for the outcome of resuscitation (n=45, 45.9%), (d) all "other" reasons, such as ethical and legal factors, and professional standards or documents (n=40, 40.8%), and (e) ensuring that families would be involved in decision-making (n=39, 39.8%). These five categories of influences were retained when the influences for no-CPR orders and for end-of-life technologies were also content analyzed.

The reliability of reported influences for DNR policies should be considered in light of two additional findings. Recall of policy influences, for policies developed as early as 1983 (the first reported date), may be a significant problem. However, as indicated, the majority of policies were developed in the 1990's; recall should not be a significant problem then. Second, 70.4 percent of the SNAs reported they had been involved in the development of theirfacility's DNR policy (see Table 6 for a listing of involved persons). Involvement by such a large proportion of SNAs reduces the possibility that reported influences were either personal opinions of SNAs about what they thought had potentiated policy, or influences relayed from other persons involved in policy development.

Table 4

Life Support Technologies and Interventions Addressed by Broad DNR Policies in Acute Care and Long-Term Care Facilities in Alberta

	Technology or intervention	n	percentage
1.	antibiotics	32	69.6%
2.	other medications	31	67.4%
3.	transfer to another facility	28	60.9%
4.	intravenous fluids or electrolytes	24	52.2%
5.	defibrillation	19	41.3%
6.	intubation and mechanical ventilation	19	41.3%
7.	oxygen therapy	18	39.1%
8.	enteral tube feeding	13	28.3%
9.	hypodermoclysis	12	26.1%
10.	other	10	21.7%

Note. Maximum score = 46.

Table 5

Influences for DNR Policies and Relationships to Type and Size of Facility

	Influence	n	percentage
A.	ensure patient involvement	47	47.9%
B.	ensure family involvement	39	39.8%
C.	professional concerns over outcome of life support	45	45.9%
D.	address decision-making process	62	63.3%
E.	other reasons	40	40.8%

Note. Maximum score = 98 for each of the five influences.

Influences in relation to type of facility

	Acute Care n(a) %	LTC n(b) %	Other n(c) %	χ^2 value	df	p
A.	16 48.5%	18 51.4%	13 43.3%	.42966	2	.80668
B.	14 42.4%	14 40.0%	11 36.7%	.21837	2	.89656
C.	17 51.5%	15 42.9%	13 43.3%	.62905	2	.73013
D.	22 66.7%	22 62.9%	18 60.0%	.30442	2	.85881
E.	17 51.5%	15 42.9%	8 26.7%	4.11047	2	.12806

Note(a). Maximum score = 33 representing all Acute Care facilities.
Note(b). Maximum score = 35 representing all LTC facilities.
Note(c). Maximum score = 30 representing all other facilities.

Table 5 (continued)

Influences for DNR Policies and Relationships to Type and Size of Facility

Influences in relation to size of facility

	Small n(d) %	Medium n(e) %	Large n(f) %	χ^2 value	df	p
A.	16 66.7%	22 43.1%	9 39.1%	4.55874	2	.10235
B.	14 58.3%	19 37.3%	6 26.1%	5.38386*	2	.06775
C.	11 45.8%	26 51.0%	8 34.8%	1.67481	2	.43283
D.	15 62.5%	33 64.7%	14 60.9%	.10839	2	.94725
E.	8 33.3%	19 37.3%	13 56.5%	3.17260	2	.20468

* significant value

Note(d). Maximum score = 24 representing all small facilities.
Note(e). Maximum score = 51 representing all medium facilities.
Note(f). Maximum score = 23 representing all large facilities.

Table 6

Persons Involved in DNR Policy Formation

Persons involved, by professional designation	n	percentage
1. nursing representative(s)	97	98.98%
2. medical representative(s)	95	96.9%
3. administrator(s)	78	79.6%
4. other person(s)	30	30.6%

Note. Maximum score = 98.

Question Two. DNR Policy Influences in Relation to the Type of Health Care Facility

No significant differences in expected versus observed frequencies were found on chi square analysis of the relationship between each of the five DNR policy influences and the type of facility (see Table 5).

Question Three. DNR Policy Influences in Relation to the Size of Health Care Facility

One significant difference was found when each of the five categorized influences for DNR policies were compared for their occurrence in relation to the size (small, medium, or large) of health care facilities (see also Table 5). The policy influence "to ensure family involvement" differed significantly (χ^2 test=5.38386, df=2, p=.06775). On further appraisal of this relationship, SNAs in smaller facilities (n=14, 58.3%), in comparison to medium sized (n=19, 26.1%) or large facilities (n=6, 26.1%), had more commonly reported policies being influenced by concerns over family involvement.

Question Four. Adherence to DNR Policies

Partial adherence to DNR policy was observed in 59 (43.1%) of the reviewed patient charts; while 42 (30.7%) had full adherence and 36 (26.3%) charts demonstrated no adherence to policy. Policy implementation problems were varied, however they commonly occurred when patients were not involved in decision-making, as was expected by policy. No-CPR and other end-of-life treatment decisions tended to be made after patients were near death and incapable of interacting. Late decisions also did not, as a rule, appear to reflect what the patients had previously preferred or requested.

Neither patient age nor gender were statistically significant in relation to whether the facility's DNR policy had been fully, partially or not adhered to. A significant relationship between type of health care facility and policy adherence was found using Pearson chi square testing (χ^2=10.21308, df=4, p=.03699). Further appraisal of this relationship revealed that the policy in the

AC/ICU hospital was most often fully adhered to (n=31, 39.7% compared to n=9, 22.5% for LTC and n=2, 10.5% for the AC/S facilities). The policies in the two AC/S facilities and the LTC facility were most often partially adhered to (n=13, 68.4%, and n=19, 47.5% respectively, in comparison to n=27, 34.6% in the AC/ICU facility). DNR policies were not adhered to in 21.1 to 30 percent of charts in the three types of facilities (see Table 7).

Question Five. End-of-Life Interventions

A number of findings in relation to end-of-life interventions are notable. In addition to the description of technologies used during the end-of-life period, the prevalence of no-CPR orders and CPR, comparisons of lengths of stay for patients, and a determination of the timing of no-CPR orders in relation to length of stay will be presented. Of all findings, it should be stressed that only 11 patients (8.0% of 137 patients) did not have a written no-CPR order in their chart. These 11 patients could have received CPR at the time of their death. There was no significant differences in the gender (χ^2=3.06300, df=2, p=.21621), age (χ^2[grouped data]=2.09989, df=4, p=.71739 and F[raw scores]=.9248, p=.3380), or type of health care facility (χ^2=3.06300, df=2, p=.21621) where these 11 patients resided. Only 4 of these patients (2 female and 2 male, all in the AC/ICU hospital) actually received CPR prior to their deaths (2.9% of all 137 patients). Patients who received CPR were considerably younger on average than the larger sample (50.0 versus 70.9 years). The vast majority of patients (n=126, 91.97%) died with a DNR designation, and with CPR having been withheld.

It should also be stressed that the length of stay significantly, and understandably, differed (see Table 8) depending on the type of facility that patients resided in (F(raw scores)=34.5021, p=.0000). The average length of stay for all 137 patients was 289.75 days; ranging from 7 to 3791 days. The length of stay was further differentiated (on average) into 22.1 days in the AC/S facilities, 23.1 days in the AC/ICU hospital, and 936.8 days in the LTC facility.

Table 7

Policy Adherence

Adherence to DNR policies	n	percentage
nil	36	26.3%
partial	59	43.1%
full	42	30.7%

Note. Maximum score = 137.

Grouped ages of patients in relation to DNR policy adherence *

	19-54 n(a)	55-64 n(b)	65-74 n(c)	75-84 n(d)	85+ n(e)
Nil	7	3	6	8	12
Partial	12	7	10	14	16
Full	9	4	5	13	11

* χ^2=1.92969 df=8 p=.98309
Spearman rho correlation =.02162 p=.80197
ANOVA F(raw scores)=.2403 p=.9151

Note (a). Maximum score = 28.
Note (b). Maximum score = 14.
Note (c). Maximum score = 21.
Note (d). Maximum score = 35.
Note (e). Maximum score = 39.

Table 7 (continued)

Policy Adherence

Gender in relation to adherence to DNR policies *

	Male n(f)	Female n(g)
Nil	18	18
Partial	27	32
Full	22	20

* χ^2=.45349 df=2 p=.79712

* ANOVA F(raw scores)=.588, p=.444

Note (f). Maximum score = 67.

Note (g). Maximum score = 70.

Type of health care facility in relation to DNR policy adherence *

	Acute Care/Small n(h)	LTC n(i)	Acute Care/ICU n(j)
Nil	4	12	20
Partial	13	19	27
Full	2	9	31

χ^2=10.21308 df=4 p=.03699

Note (h). Maximum score = 36.

Note (i). Maximum score = 59.

Note (j). Maximum score = 42.

Table 8

Length of Stay

Length of stay in relation to type of health care facility *

Acute Care/Small n(a)	Acute Care/ICU n	LTC n
22.1	23.1	936.8

* ANOVA, F(raw scores)=34.5021, p=.0000
* Spearman rho correlation=-.40050, p=.00000

Note(a). Length of stay is average number of days for each facility type.

Length of stay in relation to gender (b) *

Male n(c)	Female n
162.8	411.2

* ANOVA, F=4.2258, p=.0417
* Spearman rho correlation=.19245, p=.01426

Note(b). There were 70 women and 67 men in this sample.
Note(c). Length of stay is indicated in average number of days.

Table 8 (continued)

Length of Stay

Length of stay in relation to grouped ages of patients (d) *				
19-54	55-64	65-74	75-84	85+
n(e)	n	n	n	n
163.8	16.1	118.2	165.8	681.9

* ANOVA (raw scores), F=1.7918 p=.0082

* Spearman rho correlation=.29298 p=.00051

Note(d). The average age of patients at the time of their death was 70.9, with ages ranging from 19 to 97.

Note(e). Lengths of stay ranged from 7 days to 3791 days.

A significant relationship between gender and length of stay was also found (F(raw scores)=4.2258, p=.0417). Women, who lived longer lives on average (76.1 years compared to 65.4 years for men), had longer lengths of stay (411.1 days in comparison to 162.8 days for men). Patient age was also significantly related to the length of stay (r=.29298, p=.00051 and F(raw scores)= 1.7918, p=.0082). With one exception, advancing age appeared to indicate longer periods of hospitalization. The youngest patient group (aged 19 to 54) had an average length of stay (163.78 days) that nearly equalled that of the second oldest (aged 75 to 84) patient group (165.77 days).

No-CPR orders were written on admission through to the day of death. Neither patient gender (F=1.2217, p=.2710) nor age (r=.07181 p=.40431; F=1.5350, p=.1957) were found to have a significant relationship with the number of days between admission and the no-CPR order. The number of days between admission and the no-CPR decision differed however in relation to the type of health care facility (F=10.5797, p=.0001). No-CPR decisions were made in the AC/S hospitals, LTC facilities, and AC/ICU hospitals after 32.9 percent, 47.4 percent, and 65.2 percent of the patient stays, on average, had elapsed.

Significant differences, in expected versus observed frequencies, were also found when the number of days from the no-CPR order to death were compared for differences associated with patient gender (F=5.3011, p=.0228) and age (r=.47823, p=.00000; F=6.0214, p=.0002). The youngest patient group and the oldest patient group had no-CPR orders written later in their hospital stays (153.2 days and 302.2 days on average), in comparison to the three middle groups (7.7 days, 45.4 days, and 55.6 days on average respectively). A longer period of time between the no-CPR designation and subsequent death was also observed in female patients (222.8 days compared to 74.8 days for male patients). The length of time (in days) between the DNR order and the patient's demise was also significantly different when the type of facility was considered (r=.48879, p=.00000; F=33.5016, p=.0000). Patients lived much longer on average, with a DNR designation, in the LTC facility (492.6 days); compared to the small AC facilities (14.9 days) or the large AC/ICU hospital (7.9 days).

Despite CPR being almost universally withheld, the vast majority (n=129, 94.2%) of patients died with at least one potentially life sustaining technology in use (see Table 9). Some of these technologies were started in the last days of life, some were continued unchanged from previous times, and some had undergone changes in the last days of life (example: increased oxygen concentration). Supplementary oxygen was the most commonly used technology (n=99, 72.3%); followed by intravenous (IV) and other artificially introduced fluids and electrolytes (n=93, 67.9%), "other" extremely varied technologies (n=93, 67.9%), and enteral tube feeding (n=33, 24.1%). Additional, more "cure oriented" (Marshall, 1980a, 1980b; Miles & August, 1990), technologies were commonly discontinued just prior to the last day or two of life (such as mechanical ventilation, continuous cardiogenic intravenous medications, and chemotherapy). Another major finding was that 37 of the 78 AC/ICU patients (47.4%, or 27% of all 137 patients) had received ICU support. Only five patients actually died in the ICU; other patients were transferred out of the ICU to die (commonly one day prior to their demise).

The use of end-of-life technologies tended to vary when age, gender, and type of facility were considered (see also Table 9). Significant relationships were found between patient age and use of IVs (χ^2=21.17269, df=4, p=.00029), all "other" technologies (χ^2=8.86489, df=4, p=.06457), and ICU care (χ^2=17.00550, df=4, p=.00193). Use of technologies was highest among young persons, with use becoming less prevalent with advancing age (for example: the use of these technologies ranged from 82.1% to 35.7% for the youngest group of patients, and 59.0% to 00.00% in the oldest group of patients).

Gender differentiated the use of most end-of-life technologies. Significant relationships were found between gender and IVs (χ^2=5.69266, df=1, p=.01704), all "other" technologies (χ^2=4.07996, df=1, p=.04339), tube feeding (χ^2=5.48822, df=1, p=.01915), and ICU care (χ^2=7.06526, df=1, p=.00786). No relationship between oxygen use and gender was found (χ^2=.36564, df=1, p=.54539). Oxygen, the most frequent technology, was provided nearly as often to females (n=49, 70.0%) as to males (n=50, 74.6%). Males received more IVs (77.6%

Table 9

Technologies Used in the End-of-Life Period

Technologies used at the end-of-life	n(a)	percentage
oxygen	99	72.3%
IV	93	67.9%
other	93	67.9%
tube feeding	23	24.1%
ICU	37	27.0%(b)

Note(a). Maximum score = 137.

Note(b). 37 of 78 AC/ICU patients = 47.4%. 37 of 137 patients = 27.0%.

Grouped age in relation to end-of-life technologies

	19-54 n(c)	55-64 n(d)	65-74 n(e)	75-84 n(f)	85+ n(g)	χ^2	df	p
oxygen	23	12	15	26	23	6.14208	4	.18879
IV	23	13	17	24	16	21.17269*	4	.00029
tube feed	22	13	15	20	23	8.86489*	4	.06457
other	10	4	5	9	5	4.98302	4	.28904
ICU	14	6	6	8	3	17.00550*	4	.00193

* significant value

Note(c). Maximum score = 28.

Note(d). Maximum score = 14.

Note(e). Maximum score = 21.

Note(f). Maximum score = 35.

Note(g). Maximum score = 39.

Table 9 (continued)

Technologies Used in the End-of-Life Period

Gender in relation to end-of-life technologies

	Male n(h)	Female n(i)	χ^2	df	p
oxygen	50	49	.36564	1	.54539
IV	52	41	5.69266*	1	.01704
tube feed	51	42	4.07996*	1	.04339
other	22	11	5.48822*	1	.01915
ICU	25	12	7.06526*	1	.00786

* significant value

Note(h). Maximum score = 67.
Note(i). Maximum score = 70.

Type of health care facility in relation to end-of-life technologies

	Acute Care/Small n(j)	LTC n(k)	Acute Care/ICU n(l)	χ^2	df	p
oxygen	15	16	68	29.85484*	2	.00000
IV	12	11	70	47.21180*	2	.00000
tube feed	11	16	66	25.15004*	2	.00000
other	0	2	31	24.45443*	2	.00000
ICU	0	0	37	38.34244*	2	.00000

* significant value

Note(j). Maximum score = 19.
Note(k). Maximum score = 40.
Note(l). Maximum score = 78.

compared to 58.6% for women), "other" technologies (76.1% compared to 60.0% for women), and enteral tube feeding (32.8% compared to 15.7% for women) during the end-of-life period. Males were also cared for more often in the ICU (37.3%), in comparison to women (17.1%). These gender differences may have inadvertently occurred as a result of males tending to die at younger ages; the amount of technology in use at the time of death appeared to have an inverse relationship to aging.

The prevalence of end-of-life technologies also varied in relation to the type of facility (see Table 9). Significant differences in the expected versus actual frequencies of oxygen use in each of the three types of facilities were found (χ^2=29.85484, df=2, p=.00000); as was the case with IVs (χ^2=47.21180, df=2, p=.00000), all "other" technologies (χ^2=25.15004, df=2, p=.00000), and tube feeding (χ^2=24.45443, df=2, p=.00000). Acute care patients in general received more end-of-life technologies than did LTC patients. Patients in the AC/ICU hospital specifically, in comparison to the AC/S patients (range of 63.2% to 00.00% use of technologies) and the LTC patients (range of 40.0% to 00.00% use of technologies), received the most end-of-life technologies (89.7% to 39.7% range of technology use).

Question Six. Documented Influences for No-CPR and End-of-Life Treatment Decisions

The influences for no-CPR decisions, as determined solely through chart reviews (see Table 10), included (in order of prevalence): (a) family preferences (n=78, 56.9% of 137 charts), (b) professional concerns over the outcome of CPR (n=72, 52.6%), (c) patient preferences (n=18, 13.1%), (d) being part of a process of decision-making (n=17, 12.4%), and (e) all other reasons (n=5, 3.6%). Two influences had a significant relationship with grouped patient ages; patient preferences (χ^2=12.38656, df=4, p=.01470) and professional concerns over the outcome of CPR (χ^2=13.95276, df=4, p=.00745). "Professional concerns" was a common influence for most patients until the age of 75, after which it became

Table 10

Charted Influences for No-CPR Decisions

	Influence	n(a)	percentage
A	patient involvement	18	13.1%
B	family involvement	78	56.9%
C	professional concerns over outcome of life support	72	52.6%
D	decision-making process	17	12.4%
E	other reasons	5	3.6%

Note(a). Maximum score = 98 for each of the five influences.

Grouped age in relation to influences for No-CPR decisions

	19-54 n(b)	55-64 n(c)	65-74 n(d)	75-84 n(e)	85+ n(f)	χ^2	df	p
A	7	4	3	4	0	12.38656*	4	.01470
B	13	10	12	24	19	5.46719	4	.24263
C	19	10	14	17	12	13.95276*	4	.00745
D	2	3	4	5	3	3.52549	4	.47401
E	1	1	0	0	3	4.42011	4	.35213

* significant value

Note(b). Maximum score = 28.
Note(c). Maximum score = 14.
Note(d). Maximum score = 21.
Note(e). Maximum score = 35.
Note(f). Maximum score = 39.

Table 10 (continued)

Charted Influences for No-CPR Decisions

Gender in relation to influences for No-CPR decisions

	Male n(g)	Female n(h)	χ^2	df	p
A	8	10	.16501	1	.68458
B	37	41	.15646	1	.69244
C	41	31	3.92508*	1	.04757
D	9	8	.12652	1	.72206
E(i)	1	4	1.73514	1	.18776

Note(g). Maximum score = 67.
Note(h). Maximum score = 70.
Note(i). Small number of subjects necessitated two-tailed Fisher's Exact Test (p=.36632) to verify non-significance.

Type of health care facility in relation to influences for no-CPR decisions

	Acute Care/Small n(j)	LTC n(k)	Acute Care/ICU n(l)	χ^2	df	p
A	2	1	15	6.61715*	2	.03657
B	4	21	53	14.15696*	2	.00084
C	7	8	57	32.05720*	2	.00000
D	4	3	10	2.20506	2	.33203
E	1	2	2	.60948	2	.73732

* significant value

Note(j). Maximum score = 19.
Note(k). Maximum score = 40.
Note(l). Maximum score = 78.

much less prevalent. No-CPR decisions that were based on "patient preferences" also became much less prevalent after retirement (65+) age.

Gender was not usually a factor in the charted influences for no-CPR decisions; although a significant relationship was noted with the influence "professional concerns over patient outcomes of CPR" (χ^2=3.92508, df=1, p=.04757). Male patients were more likely to have "professional concerns" charted (n=41, 61.2% compared to n=31, 44.3% of female patients) as an influence for no-CPR decisions.

Three influences were also found to be significant when the type of facility was considered; patient requests (χ^2=6.61715, df=2, p=.03657), family requests (χ^2=14.15696, df=2, p=.00084) and professional concerns (χ^2=32.05720, df=2, p=.00000). Patient requests, family requests and professional concerns all tended to be much more frequently reported influences for no-CPR decisions in the large AC/ICU hospital.

In comparison, charted influences for end-of-life technology decisions (excluding the no-CPR decision) were infrequent (see Table 11). Only 50 of the 137 patients (36.5%) had influences, totalling 76 in number, charted for the potentially life supporting technologies they received at the end-of-life. The charted influences for these end-of-life technology decisions included: (a) professional concerns for patient outcome (n=31, 22.6% of 137 patients), (b) all other influences (n=22, 16.1%), (c) family preferences (n=14, 10.2%), (d) patient preferences (n=7, 5.1%), and (e) part of a process of decision-making (n=2, 1.5%). These influences did not tend to differ statistically when they were compared with the patients' ages, the patients' gender, or the type of facility using chi square analysis. A fairly equal distribution of influences was noted, with the exception of the type of facility and "professional concerns" (χ^2=5.82884, df=2, p=.05424) or "the decision-making process" (χ^2=4.92185, df=2, p=.08536). Professional concerns were more commonly mentioned in the AC/S (n=8, 42.1%), and less often in the LTC facility (n=10, 25.0%) and AC/ICU facility (n=13, 16.7%). The decision-making process was an influence only in the LTC facility.

Table 11

Charted Influences for End-of-Life Technology Decisions

	Influence	n(a)	percentage
A	patient involvement	7	5.1%
B	family involvement	14	10.2%
C	professional concerns over outcome of life support	31	22.6%
D	decision-making process	2	1.5%
E	other reasons	22	16.1%

Note(a). Maximum score = 137 for each of the five influences.

Grouped age in relation to influences for technology decisions

	19-54 n(b)	55-64 n(c)	65-74 n(d)	75-84 n(e)	85+ n(f)	χ^2	df	p
A	3	0	0	2	2	3.72522	4	.44447
B	3	1	1	3	6	2.07134	4	.72264
C	4	3	3	11	10	3.70984	4	.44670
D	0	0	0	0	2	5.10000	4	.27718
E	1	1	0	0	3	2.93436	4	.56887

Note(b). Maximum score = 28.
Note(c). Maximum score = 14.
Note(d). Maximum score = 21.
Note(e). Maximum score = 35.
Note(f). Maximum score = 39.

Table 11 (continued)

Charted Influences for End-of-Life Technology Decisions

Gender in relation to influences for end-of-life technology decisions

	Male n(g)	Female n(h)	χ^2	df	p
A(i)	2	5	1.22061	1	.26924
B	8	6	.42348	1	.51521
C	17	14	.56452	1	.45244
D(j)	1	1	.00097	1	.97511
E	11	11	.01257	1	.91072

Note(g). Maximum score = 67.
Note(h). Maximum score = 70.
Note(i). Small number of subjects necessitated two-tailed Fisher's Exact Test (p=.44162) to verify non-significance.
Note(j). Small number of subjects necessitated two-tailed Fisher's Exact Test (p=1.0000) to verify non-significance.

Type of health care facility in relation to influences for end-of-life technology decisions

	Acute Care/Small n(k)	LTC n(l)	Acute Care/ICU n(m)	χ^2	df	p
A	2	1	4	1.71170	2	.42492
B	1	4	9	.65873	2	.71938
C	8	10	13	5.82884*	2	.05424
D	0	2	0	4.92185*	2	.08536
E	6	5	11	3.99247	2	.13585

* significant value

Note(k). Maximum score = 19.
Note(l). Maximum score = 40.
Note(m). Maximum score = 78.

Question Seven. Recalled Influences for No-CPR and End-of-Life Treatment Decisions

The influences for no-CPR orders, obtained through interviews with 30 physicians (see Table 12), included: (a) professional concerns over the outcome of CPR (n=28, 93.3%), (b) family wishes (n=15, 50.0%), (c) patient requests (n=9, 30.0%), (d) "other" reasons (n=8, 26.7%), and (e) CPR being part of a decision-making process (n=5, 16.7%). Potential relationships between the five groups of recalled influences and patient age, patient gender, and type of facility were examined. Only the "patient requests" influence was found to significantly differ in observed versus expected frequencies (χ^2=6.66667, df=2, p=.03567) when the type of facility was considered. Physicians in AS/S hospitals more commonly related that patient requests had formulated no-CPR decisions (60%, compared to 20% in LTC and 10% in AC/ICU).

Nurse-recalled influences for no-CPR orders, similarly, were varied and numerous (see Table 13). The three most commonly nurse reported influences duplicated those recalled by physicians. The influences for no-CPR orders, noted through interviews with 30 nurses, included: (a) professional concerns for the outcome of CPR (n=25, 83.3%), (b) family requests (n=21, 70.0%), (c) patient requests (n=15, 50.0%), (d) decision-making process (n=9, 30.0%), and (e) "other" reasons (n=8, 26.7%). Relationships between the five groups of influences and patient age, patient gender, and type of facility were also examined. Only the "family preference" (χ^2=12.38095, df=2, p=.00205) influence was found to have a significant relationship with the age of patients. As patients advanced past the age of 74, family preferences became much more prevalent. No influences were significant when gender was considered. The "family preference" (χ^2=12.38095, df=2, p=.00205), "patient request" (χ^2=5.6000, df=2, p=.06081) and "other" (χ^2=6.47727, df=2, p=.03922) influences were found to have significant relationships with the type of facility. Nurses in the LTC facility recalled that family preferences had more often guided no-CPR decisions (100%, compared to 80% in AC/S or 30% in AC/ICU). Nurses in the AC/ICU hospital rarely recalled patients being involved in no-CPR decisions

Table 12

Physician Recalled Influences for No-CPR Decisions

	Influence	n(a)	percentage
A.	patient involvement	9	30.0%
B.	family involvement	15	50.0%
C.	professional concerns over outcome of life support	28	93.3%
D.	decision-making process	5	16.7%
E.	other reasons	8	26.7%

Note(a). Maximum score = 30 for each of the five influences.

Grouped age in relation to influences for no-CPR decisions

	19-54 n(b)	55-64 n(c)	65-74 n(d)	75-84 n(e)	85+ n(f)	χ^2	df	p
A	2	1	2	1	3	3.13492	4	.53551
B	4	0	2	5	4	7.20000	4	.12569
C	4	3	4	9	8	2.67857	4	.61297
D	0	0	2	2	1	1.92000	4	.38289
E	2	1	0	4	1	4.73011	4	.31613

Note(b). Maximum score = 4.
Note(c). Maximum score = 3.
Note(d). Maximum score = 5.
Note(e). Maximum score = 10.
Note(f). Maximum score = 8.

Table 12 (continued)

Physician Recalled Influences for No-CPR Decisions

Gender in relation to influences for no-CPR decisions

	Male n(g)	Female n(h)	χ^2	df	p
A(i)	3	6	1.42857	1	.23200
B	10	5	3.3333*	1	.06789
C(j)	15	13	2.14286	1	.14323
D(k)	2	3	.24000	1	.62421
E(l)	4	4	.00000	1	1.0000

Note(g)(h). Maximum score = 15.

Note(i). Small n necessitated two-tailed Fisher's Exact Test (p=.42699).

Note(j). Small n necessitated two-tailed Fisher's Exact Test (p=.48276).

Note(k). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).

Note(l). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).

Type of health care facility in relation to physician recalled influences

	Acute Care/Small n(m)	LTC n(n)	Acute Care/ICU n(o)	χ^2	df	p
A	6	2	1	5.75397*	1	.01645
B	5	6	4	.19333	1	.66016
C	9	10	9	.00000	1	1.0000
D	1	1	3	1.39200	1	.23807
E	1	4	3	.98864	1	.32008

* significant value

Note(m). Maximum score = 10.

Note(n). Maximum score = 10.

Note(o). Maximum score = 10.

Table 13

Nurse Recalled Influences for No-CPR Decisions

	Influence	n(a)	percentage
A.	patient involvement	15	50.0%
B.	family involvement	21	70.0%
C.	professional concerns over outcome of life support	25	83.3%
D.	decision-making process	9	30.0%
E.	other reasons	8	26.7%

Note(a). Maximum score = 30 for each of the five influences.

Grouped age in relation to influences for no-CPR decisions

	19-54 n(b)	55-64 n(c)	65-74 n(d)	75-84 n(e)	85+ n(f)	χ^2	df	p
A	2	1	3	4	5	1.43333	4	.83838
B	2	2	1	10	6	11.1111*	4	.02534
C	4	3	4	9	5	4.26000	4	.37196
D	1	2	0	3	3	4.32540	4	.36376
E	2	1	0	4	1	2.42898	4	.65740

* significant value

Note(b). Maximum score = 4.
Note(c). Maximum score = 3.
Note(d). Maximum score = 5.
Note(e). Maximum score = 10.
Note(f). Maximum score = 8.

Table 13 (continued)

Nurse Recalled Influences for No-CPR Decisions

Gender in relation to influences for no-CPR decisions

	Male n(g)	Female n(h)	χ^2	df	p
A	8	7	.13333	1	.71500
B(i)	10	11	.15873	1	.69033
C(j)	13	12	.24000	1	.62421
D(k)	3	6	1.42857	1	.23200
E(l)	5	3	.68182	1	.40896

Note(g)(h). Maximum score = 15.

Note(i). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).

Note(j). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).

Note(k). Small n necessitated two-tailed Fisher's Exact Test (p=.42699).

Note(l). Small n necessitated two-tailed Fisher's Exact Test (p=.68166).

Type of health care facility in relation to nurse recalled influences for no-CPR decisions

	Acute Care/Small n(m)	LTC n(n)	Acute Care/ICU n(o)	χ^2	df	p
A	7	6	2	5.60000*	2	.06081
B	8	10	3	12.38095*	2	.00205
C	8	7	10	3.36000	2	.18637
D	2	5	2	2.85714	2	.23965
E	0	5	3	6.47727*	2	.03922

* significant value

Note(m)(n)(o). Maximum score each = 30

(20%, compared with 60% in the LTC facility and 70% in the AC/S hospitals). Nurses in the AC/S facility did not recall any "other" reasons for no-CPR decisions (in comparison to 50% in the LTC and 30% in the AC/ICU hospital).

Agreement, on the influences for no-CPR decisions, between nurses and physicians was common (see Table 14). The only exception to this was a difference in the frequency of recalled "patient requests" (Fisher's two-tailed Exact test, p=.01419). Nurses recalled "patient requests" more often (n=15, 50%, compared to n=9, 30% for physicians). The prevalence of no-CPR influences recalled by physicians, however, did not significantly differ from those recorded on the chart (see Table 14). Furthermore, the prevalence of no-CPR influences recalled by nurses was also not significantly different from those recorded on the chart (see Table 14). All three sets of almost consensual data indicated that "professional concerns over the outcome of CPR" and "family preferences" were the most common influences for no-CPR decisions.

A shift in the influences for no-CPR orders to the influences for end-of-life technologies was then observed. End-of-life technology decisions according to 30 interviewed physicians (see Table 15), were based on (a) professional concerns for the outcomes of life support (n=18, 60.0%), (b) all "other" reasons (n=17, 56.7%), (c) family requests (n=12, 30.0%), (d) being part of a process of decision-making (n=9, 30.0%), and (e) patient preferences or requests (n=3, 10.0%). "Other" reasons were primarily related to the promotion of patient comfort while the patient was dying. Potential relationships between the five groups of influences and patient age, patient gender, and type of facility were then examined. Only three physician recalled influences were noted to be significant; "family requests" and type of facility (χ^2=7.5000, df=2, p.=.02352), "decision-making process" and type of facility (χ^2=6.66667, df=2, p=.03567) and "the decision-making process" and patient age (χ^2=9.4444, df=4, p=.05090). "Family requests" were more likely to be recalled by physicians in the AC/ICU facility (70%, compared to 40% in LTC or 10% in AC/S). The "decision-making process" was more likely to be mentioned by physicians in the AC/ICU hospital (60% compared to 20% in the AC/S and 10% in the LTC facility). The

Table 14

Relationships between Nurse, Physician and Charted No-CPR Decision Influences

Influence	Physician n(a)	Nurse n(b)	χ^2	df	p
patient involvement(c)	9	15	7.77778*	1	.00529
family involvement(d)	15	21	1.42857	1	.23200
professional concerns(e)	28	15	.42857	1	.51269
decision-making process(f)	5	9	.28571	1	.59298
other reasons(g)	8	8	3.03719*	1	.08138

* significant value

Note(a)(b). Maximum score = 30 for each of the five influences.
Note(c). Small n necessitated two-tailed Fisher's Exact Test (p=.01419).
Note(d). Small n necessitated two-tailed Fisher's Exact Test (p=.42699).
Note(e). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(f). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(g). Small n necessitated two-tailed Fisher's Exact Test (p=.15799).

Table 14 (continued)

Relationship between Nurse, Physician and Charted No-CPR Decision Influences

Influence	Physician n(h)	Chart n(i)	χ^2	df	p
patient involvement(j)	9	18	.40816	1	.52290
ensure family involvement	15	78	2.22222	1	.13604
professional concerns(k)	28	72	.16405	1	.68546
decision-making process(l)	5	17	.23077	1	.63095
other reasons(m)	8	5	.59659	1	.43988

Note(h). Maximum score = 30 for each of the five influences.
Note(i). Maximum score = 137 for each of the five influences.
Note(j). Small n necessitated two-tailed Fisher's Exact Test (p=.51724).
Note(k). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(l). Small n necessitated two-tailed Fisher's Exact Test (p=.53841).
Note(m). Small n necessitated two-tailed Fisher's Exact Test (p=.46897).

Influence	Nurse n(n)	Chart n(o)	χ^2	df	p
patient involvement(p)	15	18	2.14286	1	.14323
ensure family involvement(q)	21	78	1.69312	1	.19319
professional concerns(r)	25	72	1.40670	1	.23561
decision-making process(s)	9	17	.05495	1	.81467
other reasons(t)	8	5	.77922	1	.37738

Note(n). Maximum score = 30 for each of the five influences.
Note(o). Maximum score = 137 for each of the five influences.
Note(p). Small n necessitated two-tailed Fisher's Exact Test (p=.48276).
Note(q). Small n necessitated two-tailed Fisher's Exact Test (p=.24871).
Note(r). Small n necessitated two-tailed Fisher's Exact Test (p=.32683).
Note(s). Small n necessitated two-tailed Fisher's Exact Test (p=1.2000).
Note(t). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).

Table 15

Physician Recalled Influences for End-of-Life Technology Decisions

	Influence	n(a)	percentage
A	patient involvement	3	10.0%
B	family involvement	12	30.0%
C	professional concerns over outcome of life support	18	60.0%
D	decision-making process	9	30.0%
E	other reasons	17	56.7%

Note(a). Maximum score = 30 for each of the five influences.

Grouped age in relation to influences for technology decisions

	19-54 n(b)	55-64 n(c)	65-74 n(d)	75-84 n(e)	85+ n(f)	χ^2	df	p
A	0	0	0	1	2	3.33333	4	.50367
B	2	2	2	4	2	1.80556	4	.77147
C	2	2	4	5	5	1.49306	4	.82787
D	3	2	1	3	0	9.44444*	4	.05090
E	2	3	3	4	5	3.63122	4	.45821

* significant value

Note(b). Maximum score = 4.
Note(c). Maximum score = 3.
Note(d). Maximum score = 5.
Note(e). Maximum score = 10.
Note(f). Maximum score = 8.

Table 15 (continued)

Physician Recalled Influences for End-of-Life Technology Decisions

Gender in relation to influences for end-of-life technology decisions

	Male n(g)	Female n(h)	χ^2	df	p
A(i)	2	1	.37037	1	.54280
B	7	5	.55556	1	.45606
C	8	10	.55556	1	.45606
D(j)	6	3	1.42857	1	.23200
E	7	10	1.22172	1	.26902

Note(g)(h). Maximum score = 15.

Note(i). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).

Note(j). Small n necessitated two-tailed Fisher's Exact Test (p=.42699).

Type of health care facility in relation to physician recalled influences for end-of-life technology decisions

	Acute Care/Small n(k)	LTC n(l)	Acute Care/ICU n(m)	χ^2	df	p
A	1	1	1	.00000	2	1.0000
B	1	4	7	7.5000*	2	.02352
C	4	60	8	3.3333	2	.18888
D	2	1	6	6.66667*	2	.03567
E	7	6	4	1.90045	2	.38665

* significant value

Note(k). Maximum score = 10.

Note(l). Maximum score = 10.

Note(m). Maximum score = 10.

"decision-making process" influence was less often mentioned by physicians as the patient's age increased (75% for patients under the age of 55, 66.7% for 55-64, 20.0% for 65-74, 30.0% for 75-84, and 00.00% for 85+).

End-of-life technology decision influences recalled by nurses were also varied, and were again similar to those recalled by physicians (see Table 16). Influences, in order of prevalence, included (a) all "other" reasons (n=17, 56.7%), (b) professional concerns over the outcome of life support (n=15, 50.0%), (c) family requests (n=14, 46.7%), (d) part of a process of decision-making (n=12, 40.0), and (e) patient preferences or requests (n=5, 16.7%). "Other" reasons were also primarily related to the promotion of patient comfort while the patient was dying. Only two nurse recalled influences were noted to be significant, using chi square analysis, in relation to patient age, gender, and type of facility. The "other" influence had a borderline significant relationship with gender (40% of males and 73.3% of females had this influence recalled by nurses). The professional concern for patient outcome also had a borderline significant relationship with the type of facility (30% in LTC facility, 40% in the AC/S hospitals, and 80% in the AC/ICU hospital).

Agreement between nurses and physicians, on end-of-life treatment decision influences, was common (see Table 17). The only influence recalled in somewhat differing frequencies was that of the "family preference" (χ^2=3.21429, df=2, p=.07300). The influences for end-of-life technology decisions recalled by physicians and nurses also closely resembled charted end-of-life technology influences. Only one significant relationship was found; the "other" influence differed statistically between physician recalled and charted end-of-life influences (Fisher's two-tailed exact test, p=.03245). Physicians more often recalled "other" influences (mainly those related to patient comfort promotion while dying) in comparison to charted influences (n=17, 56.7% in comparison to n=22, 16.1%). All three sets of data indicate that the "professional concerns over the outcome of life support" and all "other" reasons had most frequently influenced technology decisions at the end-of-life.

Table 16

Nurse Recalled Influences for End-of-Life Technology Decisions

	Influence	n(a)	percentage
A	patient involvement	5	30.0%
B	family involvement	14	46.7%
C	professional concerns over outcome of life support	15	50.0%
D	decision-making process	12	40.0%
E	other reasons	17	56.7%

Note(a). Maximum score = 30 for each of the five influences.

Grouped age in relation to influences for end-of-life decisions

	19-54 n(b)	55-64 n(c)	65-74 n(d)	75-84 n(e)	85+ n(f)	χ^2	df	p
A	0	1	1	1	2	2.16000	4	.70636
B	3	1	2	5	3	1.90848	4	.75259
C	2	2	4	4	3	3.03333	4	.55226
D	1	2	2	5	2	2.43056	4	.65711
E	2	2	2	4	7	4.98869	4	.28846

Note(b). Maximum score = 4.
Note(c). Maximum score = 3.
Note(d). Maximum score = 5.
Note(e). Maximum score = 10.
Note(f). Maximum score = 8.

Table 16 (continued)

Nurse Recalled Influences for End-of-Life Technology Decisions

Gender in relation to influences for end-of-life technology decisions

	Male n(g)	Female n(h)	χ^2	df	p
A(i)	3	2	.24000	1	.62421
B	8	6	.53571	1	.46421
C	9	6	1.20000	1	.27332
D	7	5	.55556	1	.45606
E	6	11	3.39367	1	.06545

Note(g)(h). Maximum score = 15.

Note(i). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).

Type of health care facility in relation to nurse recalled influences for end-of-life technology decisions

	Acute Care/Small n(j)	LTC n(k)	Acute Care/ICU n(l)	χ^2	df	p
A	3	1	1	1.92000	2	.38289
B	4	4	6	1.07143	2	.58525
C	4	3	8	5.60000	2	.06081
D	3	3	6	2.50000	2	.28650
E	5	8	4	3.52941	2	.17124

* significant value

Note(j). Maximum score = 10.

Note(k). Maximum score = 10.

Note(l). Maximum score = 10.

Table 17

Relationships between Nurse, Physician and Charted End-of-Life Technology Decision Influences

Comparison of Physician and Nurse Influences

	Influence	Physician n(a)	Nurse n(b)	χ^2	df	p
A	patient involvement(c)	3	5	.66667	1	.41422
B	family involvement	12	14	3.21429*	1	.07300
C	professional concerns	18	15	.55556	1	.45606
D	decision-making process(d)	9	12	1.29630	1	.25489
E	other reasons	17	17	1.03253	1	.30956

Note(a)(b). Maximum score = 30 for each of the five influences.
Note(c). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(d). Small n necessitated two-tailed Fisher's Exact Test (p=.41811).

Comparison of Physician and Chart Influences

Influence	Physician n(e)	Chart n(f)	χ^2	df	p
A(g)	3	7	.16515	1	.68445
B(h)	12	14	.59595	1	.44013
C(i)	18	31	.42060	1	.51664
D(j)	9	2	.14271	1	.70560
E(k)	17	22	5.32753*	1	.02099

* significant value

Note(e). Maximum score = 30 for each of the five influences.
Note(f). Maximum score = 137 for each of the five influences.
Note(g). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(h). Small n necessitated two-tailed Fisher's Exact Test (p=.35311).
Note(i). Small n necessitated two-tailed Fisher's Exact Test (p=.76318).
Note(j). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(k). Small n necessitated two-tailed Fisher's Exact Test (p=.03245).

Table 17 (continued)

Relationship between Nurse, Physician and Charted End-of-Life Treatment Decision Influences

Comparison of Nurse and Chart Influences

Influence	Nurse n(l)	Chart n(m)	χ^2	df	p
A(n)	5	4	.20690	1	.64921
B(o)	14	14	1.48867	1	.22242
C(p)	15	31	1.42857	1	.23200
D(q)	12	2	.19484	1	.65891
E(r)	17	22	.80365	1	.37000

Note(l). Maximum score = 30 for each of the five influences.
Note(m). Maximum score = 137 for each of the five influences.
Note(n). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(o). Small n necessitated two-tailed Fisher's Exact Test (p=.31545).
Note(p). Small n necessitated two-tailed Fisher's Exact Test (p=.42699).
Note(q). Small n necessitated two-tailed Fisher's Exact Test (p=1.0000).
Note(r). Small n necessitated two-tailed Fisher's Exact Test (p=.47701).

Question Eight. Comparison of DNR Policy, No-CPR, and End-of-Life Technology Influences

DNR policies, no-CPR decisions, and end-of-life technology decisions were based on one or more of the five identified influences. Some influences, however, were more prevalent than others. Only one DNR policy influence, "improving the decision-making process", was reported by the majority of SNAs. The second most frequently reported influence for DNR policies was the need to ensure patient involvement in decision-making. Low policy adherence in general was then determined through chart reviews. Furthermore, when the influences for actual no-CPR orders were reviewed, the two most commonly reported DNR policy influences were no longer prominent. Honouring "family wishes" and acting on "professional concerns for the outcome of CPR" became the two most prominent charted and recalled reasons for no-CPR decisions. A second, less dramatic, shift in influence was noted for end-of-life technology decisions. For end-of-life technologies, the two most commonly charted or recalled influences were "professional concerns for the outcome of life supports" and all "other reasons" (patient comfort measures constituted the most common reason).

These shifts in influences from DNR policy to no-CPR decisions and end-of-life treatment decisions were analyzed for their significance using analysis of variance testing (see Table 18). Having found common agreement between the prevalence of influences recalled by nurses and physicians and as noted in the chart, a decision was made to group nurse, physician, and chart influences for both the no-CPR and the end-of-life technology decisions. It was also felt important to group these three sets of scores since charting was brief and non-contextual. Interviews contributed additional influences for no-CPR and end-of-life technology decisions. Three potential relationships were specifically assessed; that of the (a) DNR policy influences and no-CPR influences, (b) DNR policy influences and end-of-life technology influences, and (c) no-CPR influences and end-of-life technology influences.

A significant relationship between DNR policy influences and

Table 18

Relationships of DNR Policy Influences, Combined No-CPR Influences, and Combined End-of-Life Technology Decision Influences

Comparison of DNR Policy and No-CPR Decision Influences

Influence	DNR Policy n(a)	Combined No-CPR Decision n(b)	ANOVA value	p
patient involvement	47	32	3.4097*	.0679
family involvement	39	90	.3047	.5822
professional concerns	45	83	.1131	.7373
decision-making process	62	28	4.2513*	.0419
other reasons	40	16	1.0431	.3097

* significant value

Comparison of DNR Policy and End-of-Life Technology Decision Influences

Influence	DNR Policy n(a)	Combined End-of-Life Technology Decision n(c)	ANOVA value	p
patient involvement	47	15	.2114	.6467
family involvement	39	28	.9961	.3208
professional concerns	45	47	.6830	.4106
decision-making process	62	18	1.6859	.1973
other reasons	40	39	.5257	.4702

Note(a). Maximum score = 98 for each of the five influences.
Note(b). Maximum score = 137 for each of the five influences.
Note(c). Maximum score = 137 for each of the five influences.

Table 18 (continued)

Relationships of DNR Policy Influences, Combined No-CPR Influences, and Combined End-of-Life Technology Decision Influences

Comparison of No-CPR and End-of-Life Technology Decision Influences

Influence	Combined No-CPR n(a)	Combined End-of-Life Technology Decision n(c)	ANOVA value	p
patient involvement	32	15	19.9626*	.0000
family involvement	90	28	9.1447*	.0030
professional concerns	83	47	8.0186*	.0053
decision-making process	28	18	.6799	.4111
other reasons	16	39	10.9793*	.0012

* significant value

Note(b). Maximum score = 137 for each of the five influences.
Note(c). Maximum score = 137 for each of the five influences.

no-CPR influences was noted, the "process of decision-making" (F=4.2513, p=.0419). Upon further appraisal of this relationship; the process of decision-making had been the most frequently reported influence for DNR policies and one of the least frequently reported no-CPR decision influences. A second, borderline, significant relationship between DNR policy influences and no-CPR influences was also noted, the "patient involvement" (F=3.4097, p=.0679). Upon further appraisal of this relationship; the second most prevalent influence for DNR policies had been to involve patients in decision-making which was in contrast to the infrequent actual involvement of patients in no-CPR decisions.

No significant relationships between DNR policy influences and influences for end-of-life technology decisions were found. Four significant relationships were found, however, when grouped influences for no-CPR decisions and grouped influences for end-of-life technology decisions were compared; the "patient request" (F=19.9626, p=.0000), the "family request" (F=9.1447, p=.0030), the "professional concerns for the outcome of life support" (F=8.0186, p=.0053), and all "other" reasons (F=10.9793, p=.0012). On closer analysis the "decision-making process" was an infrequent influence in both end-of-life technology and no-CPR decisions; it could be expected that there would not be a significant difference between these two. The four other influences varied between no-CPR and end-of-life technology decisions.

Chapter V
Discussion

The rapid introduction of CPR in the 1960s and other life-sustaining technologies since then has potentiated widespread life support utilization. Societal expectations to preserve life "at all costs" (Lindsay, 1991) also contributed to a now demanding life support problem. The problem simply stems from the difficulty in making decisions to either implement life support or to let death occur. All too frequently, life maintenance is the only outcome of life support. Recognition of this problem lead to the development of the Joint Statement (1984) and other professional documents which support withholding and withdrawing life support in specified cases; public recognition of the need for patients to be involved in health care decisions; and common law rulings which have allowed the removal of life support and supported autonomous patient wishes for the prevention of life support interventions. Health care policies and practices may also be changing, as health care professionals and health facility administrators become increasingly more aware of, and react to, this problem. This research investigation surveyed DNR policies and end-of-life treatment and non-treatment decisions, with a particular concentration on the influences for these policies and decisions. The subsequent discussion focuses specifically on: (a) the target population and samples, (b) the incidence, content, and prevalence of DNR policies, (c) the incidence of CPR and no-CPR orders, and the influences for no-CPR decisions, (d) the incidence of end-of-life technologies and the influences for these technologies, and (e) the contributions to this study from the conceptual framework.

Target Population and Samples

The study was confined to Alberta, which limits the possibility of extraneous findings and provides a basis for future study of the impact of ATD legislation. All accredited AC and LTC facilities, based on information from Canadian Hospital Association directories (1990, 1991), were surveyed. It is

possible that some accredited facilities were inadvertently not surveyed, since eight of the listed and therefore surveyed facilities were found to lack accreditation. The high return rate of questionnaires (81.7%) however, reduces the effect of incomplete sampling. Furthermore, facilities from which a survey was not returned did not overrepresent one type or size of facility. Another possible sampling concern relates to the finding that numerous facilities were classified by SNAs as being other than primarily an AC or a LTC facility. The type of facility was not found to be significant, using statistical testing, for DNR policy formation. Concerns over sampling and classification of facilities were thus mitigated. In summary, a wide sample of AC and LTC facilities in Alberta, reflecting the larger population, was accomplished.

The sample of 137 deceased patients reflects the aging populations of Alberta and Canada. The lifespans of the sampled female patients (76.1 years on average) and male patients (65.4 years on average) were shorter however than the common life expectancies reported for males (73.0 years) and females (80.0 years) in both Alberta and in Canada as a whole (Alberta Senior Citizens Secretariat, 1990; Statistics Canada, 1991). Furthermore, the average lifespans of sampled men and women differed by 10.7 years, which exceeds the 7.0 year difference reported for Albertans and Canadians. The age difference between males and females in this study was not believed to be a sampling error, but occurred through chance. Dissimilarities in illness, hospitalization, and accident rates between sampled women and men may account for this age differentiation. Approximately one half of the sample were women and one half were men, which reflects a random and natural distribution.

The vast majority of sampled adult inpatients died in an AC facility (n=97, 70.8%), which may or may not reflect the common experience of dying Albertans. No information is available for comparison. Many more deaths may actually occur in the numerous LTC facilities across Alberta. Home deaths may also be common. It should also be stressed that many of these sampled AC patients were aware of their terminal illness on admission to hospital. In one poignant case, a male patient simply was reported to have said on admission, "I

have come here to die". The documented admission comment from another patient was that she was too much of a burden on her family and that she needed hospitalization to die comfortably and without causing problems for her loved ones.

The third sample of 30 patients was representative of the larger sample (n=137). Patient ages and genders were comparable, although the lengths of stay of the larger and smaller group differed. The AC/ICU patients in the larger sample had longer hospitalizations than did the AC/S patients, a finding that was reversed in the smaller sample. This difference was not perceived to be a sampling problem, but one of random chance only. The use of two small AC facilities to gather data similarly did not appear to be a sampling or design problem, instead it reiterated the fact that all small AC facilities have dying patients and that end-of-life patient care is commonly provided. Finally, 60 health care professionals were readily found and subsequently, openly discussed the influences for end-of-life patient care decisions. It should also be stressed that there was common agreement between nurses and physicians, as well as between health care professionals and charts, on the influences that had affected no-CPR and end-of-life technology decisions. Concerns over reliability of recalled influences, as well as differences between written and verbal data are thus also allayed. Since health care professionals were not the focus of investigation, no data describing them, in ways other than their professional designation, were gathered. It was noted however, that all nurses were female, and all but two physicians were male.

DNR Policies; Incidence, Content and Influences

Finding DNR policies in 98 (72.6%) of the surveyed AC and LTC facilities indicates that DNR policies have become an accepted and common institutional tool. This prevalent trend is of relatively recent origin however. The majority of SNAs reported that their policy had been developed in the 1990s. Furthermore, another 12 facilities (8.9%) reported that they were currently drafting one. This continuing trend of policy development is also substantiated through a

comparison of this survey's findings with Singer's July 1991 survey of Canadian AC DNR policies. In Singer's survey, 57 percent of Alberta AC hospitals, in contrast to a national average of 51 percent and provincial ranges of 17 to 79 percent, reported DNR policies (personal communication, P. A. Singer, May 31, 1993). This study, in comparison, found 53 out of the 70 (63.9%) responding AC hospitals to have a DNR policy (using the same 1991 Canadian Hospital Association directory as a guide to defining AC facilities).

This study also found 45 of the 65 (60.9%) responding LTC facilities to have a DNR policy (using the 1990 Canadian Hospital Association directory as a guide to defining LTC facilities). The slight difference in incidence of DNR policies in sampled AC and LTC facilities (i.e. 63.9% to 60.9%) was unlike an earlier American survey that reported finding DNR policies in 56.9% of AC facilities but only 20.1% of LTC facilities (Longo et al., 1988a). No figures are yet available for comparison on the incidence of LTC DNR policies from Singer's 1992 survey (personal communication, P. A. Singer, May 31, 1993). In summary, the trend of policy development in Alberta appears to be relatively recent and shared equally by AC and LTC facilities.

It is difficult, however, to understand why this trend of DNR policy creation has occurred, and continues to occur. As indicated, there are no accreditation or legal requirements for DNR policies in Canada. The type of facility was not influential in whether a DNR policy would or would not be present. The size of the facility was somewhat influential, with 92 percent of large facilities having a policy in comparison to 68 percent of facilities that were smaller in size. Numerous foundational influences, in addition to size, were also discovered to have potentiated DNR policy. Of these, improving the process of decision-making was the predominant influence. It is not surprising that this be the major focus, since the purpose of policy is to standardize or routinize practice within an organization. The second most common influence was to ensure the involvement of patients in decision-making. Whether this patient influence reflects societal awareness of an ethical principal (autonomy) or an awareness of the legal right of patients for self-determination (Storch, 1982) is not known.

Professional concerns over the outcome of resuscitation, all infrequently mentioned and therefore grouped "other" influences, and to need to involve the family in decision-making were also reported (in that order) to have influenced DNR policies. These influences, with the exception of the "family" influence, were common to all facilities, regardless of size or type of facility (including whether or not ICU technologies were present). The "family" was recognized more often by smaller facilities and less often by larger ones as a variable for policy development. It is probable that the patient's family is more visible to the persons who develop DNR policies in small facilities. Families, however, were found to have played a major role in actual no-CPR decisions, particularly so in the large AC/ICU facility.

The DNR policy influences which were outlined by this survey appear to largely simulate previously reported ones, in particular the concerns over an optimized decision-making process. However, although this study did find some evidence that professional standards and documents played a part in DNR policy development in Alberta, their role was minimal (in comparison to their key role noted for example by Miles and Moldow in 1984). Only two SNAs in this study reported that the Joint Statement (1984) had influenced policy, and no other documents or standards of any kind were mentioned. Legal protection of the facility (as previously reported by: Fader et al., 1989; McPhail et al., 1981; Quill, 1989; Thom, 1988) may have also potentiated DNR policy development but, as indicated, this also was not obvious from the data.

The content of surveyed policies, in keeping with the two most common influences for DNR policies, was clearly aimed at standardizing and perhaps improving the process of decision-making; as well as its collateral purpose of increasing the involvement of patients (or their surrogate decision-makers) in decision-making. DNR policies may have been developed then to correct recognized practice problems. The chart reviews and interviews with health care professionals did reveal that patients were rarely involved (directly or indirectly) in actual end-of-life decisions. It is possible that patients generally do not wish to make life support decisions, and instead prefer to leave these

decisions to others. It could also be that patients are discouraged from making decisions, although it is clear that most DNR policies aim to facilitate patient involvement.

The PI's determination that two thirds of surveyed patient charts demonstrated only "partial" or "no" adherence to an established DNR policy also indicates that policy implementation problems are common. Problems usually related to a lack of patient involvement as a result of the late timing of decision-making. No-CPR decisions tended to occur, with some variance depending on the type of facility, after a considerable proportion of the hospitalizations had elapsed. Previous studies have also reported that near-death end-of-life decision-making is common practice (examples: Bedell & Delbanco, 1984; Bedell et al., 1986).

It is perplexing that almost all surveyed SNAs (n=90, 91.8%) reported their facility's DNR policy represented "what was practised" in that facility. SNA perceptions may be faulty or it may be that policies are not expected to be rigidly adhered to. Although evaluative studies of health care policy implementation are uncommon, it is evident that policies tend not to be implemented either in full or in part (examples: Aidroos, 1986; Bedell et al., 1986; Berland, 1990; Birnbaum, Schulzer, Mathias, Kelly & Chow, 1990; Crocker, 1987; Dalton et al., 1992; Dundas, Young & Davis, 1988; Fader et al., 1989; Kirchhoff, Westrak, Chenelly & McLane, 1988; Lo et al., 1986; Molloy & Guyatt, 1991; Shields, 1989). Kirchoff et al. (1988) indicated that partial policy adherence was not a problem since it reflected the context of the situation and the individualness of each patient, as well as the unique capabilities of each nurse. Goff (1992), Miles et al. (1982), Wear (1991), and Younger (1987) similarly recommend that each patient case be considered on an individual basis, since ethical implications and other factors vary from patient to patient. Other authors advocate a new system of decision-making. Carse (1991) feels it is time to stop relying on "principle-driven...institutionally developed rights-based codes and procedures... (and) rule-dependence" (p. 20). An ethic of care

instead is advocated, as improved dialogue with patients is believed to ensue from compassion and attention to contextual factors (Carse, 1991).

This study indicated that there is minimal full DNR policy implementation. It did not appear however that the context of each patient situation affected when DNR decisions were made, since decisions as a rule tended to be made near death and after all treatment options had failed. "Caring" and the context of each patient's situation may have lead health care professionals to withhold CPR however.

There may however be a common belief in Alberta's health care facilities that policies do direct practice. Involving a nursing representative (98%), physician representative (96.9%), facility administrators (79.6%), and others (30.6%) in DNR policy development (as reported by SNAs) demonstrates the multi-disciplinary nature of health care planning. However, this manner of policy development may create a situation similar to that demonstrated by other studies (such as Bedell et al., 1986; Honan et al., 1988; McPhail et al., 1981). A policy may be created but few facility personnel are actually aware of the policy. Furthermore, a policy may be created, but few facility personnel feel it is applicable to practice.

The focus of the DNR policies in the four health care facilities where charts were surveyed may have also contributed to non-compliance with policy. These four facilities had narrowly defined, no-CPR only, policies. Almost one half of all surveyed DNR policies in Alberta were reported, however, to address other potentially life supporting interventions (in addition to CPR). Most of these broadly focused DNR policies were developed since 1991, slightly later than the 1990 median for all DNR policies. Singer, in his 1991 survey, found only five percent of AC facilities across Canada had broad CPR policies (personal communication, P. A. Singer, June 23, 1992). It would appear that Alberta has an established trend of broad policy development. These policies may more adequately address the myriad of life support decisions made for each patient.

In summary, while DNR policies were found to be common in both LTC and AC facilities, and appear to becoming even more prevalent in Alberta, it is not

evident whether they actually influence life support decision-making. Other influences may have much more of an effect on end-of-life patient care decisions.

CPR Incidence, No-CPR Order Incidence and Influences

Only four of the 137 surveyed patients (2.9%) received CPR during their end-of-life hospitalization. Only two of these cases involved CPR at the very end of their life however. Two patients after earlier receiving CPR did not again have CPR when their lives ended after an extended hospitalization. CPR was found to be a rare form of life support, a finding which may indicate that withholding CPR is now accepted practice. Health facility policies common support withholding CPR, as apparently do the health care professionals and family members involved in actual no-CPR decisions. Most patients (n=133, 97.1%) did not receive CPR during their end-of-life hospitalization. Most patients (n=126, 91.97%), regardless of their age, gender or the type of health care facility, had a no-CPR order that was written at some point in that hospitalization. This finding contrasts with earlier accounts that 66 to 75 percent of patients in hospitals died without CPR and with a no-CPR order in their charts (Bedell & Delbanco, 1984; Bedell et al., 1986; Lipton, 1986; Schwartz & Reilly, 1986; Taffet et al., 1988).

A written no-CPR order however was not entirely necessary for CPR to be withheld, as 11 patients did not have a written no-CPR order on their chart, but CPR was still withheld from 7 of these patients upon death. This finding also supports the premise that withholding life support, or at least CPR, is now an accepted practice. This is particularly so since these 11 patients could not be differentiated from the larger sample by gender, age, or the type of facility they had passed away in. The need for DNR policies to encourage withholding of CPR is not substantiated by this finding.

The four patients who received CPR differed from the larger sample in two regards. As indicated, they were much younger on average. They also experienced what appeared to be unexpected, sudden heart and/or breathing

cessation. Kastenbaum (1991) reported that the Glaser-Strauss research team found three common dying trajectories: lingering, expected quick, or unexpected quick. The nature of illness underlying the dying trajectory may contribute in great part to the success or failure of CPR. CPR, although more likely to be used and therefore more likely to be useful in unexpected quick deaths, was still unfortunately incapable of restoring the lives of these four patients. Other investigations have similarly found CPR to be commonly ineffectual for restoring life (examples: Bedell et al., 1983; Taffet et al., 1988; Uhlmann et al., 1984).

The 133 patients who did not receive CPR, in contrast to the 4 patients who did, experienced either a lingering or expected quick death. It is evident that the time available for end-of-life decisions varies considerably as a result of the dying trajectory. The importance of care planning on or before admission is emphasized by the unforseen speed at which death approaches. The increasing effectiveness of health care, as well as the continuing chronicity of illnesses and aging of Albertans, can be expected to contribute to this phenomenon of "expected" deaths. Unexpected deaths however will still unfortunately occur, which emphasizes the importance of ATDs or living wills and the need for some available persons to be trained in CPR. This study suggested however that time was generally available in which to make most no-CPR decisions. This amount of time did not generally allow the involvement of patients in decision-making. This is particularly interesting in light of the lengthy end-of-life hospitalizations that were observed and the common AC patient involvement at the beginning of those hospitalizations.

The timing of no-CPR decisions varied in relation to the type of facility, as well as the age and gender of patients. Female patients, who tended to be older at the time of death, had comparatively earlier no-CPR decisions (since they lived for longer periods of time after these decisions were made). Decisions to withhold CPR were made closer to the time of death for male patients and for younger patients. Younger patients of both sexes, and male patients (who tended to be younger) may have later no-CPR decisions as a consequence of a

societally derived criterion for productivity potential. As early as 1975, Crane found that the capacity for patients to perform expected social roles was an influence for physicians making life support decisions. If this were so, older patients, even if performing grandparenting roles or other "retirement" roles may have comparatively earlier no-CPR decisions made since they are not deemed to be "productive". Advanced age has generally been established to be a significant variable in no-CPR decisions (examples: Bedell et al., 1986; Farber et al., 1984; Frampton & Mayewski, 1987; Pearlman et al., 1982; Thom, 1988; Witte, 1984; Younger et al., 1985). Advanced age has only been indicated however, in past studies, to influence whether a no-CPR decision was made. Aging and gender differentiation however appear to be factors in the timing of no-CPR decisions. A recent change from past decision practices, where no-CPR decisions were less commonly made and therefore more variable, is indicated by these findings.

The timing of decisions to withhold CPR was also found to relate to the type of health care facility. The small AC hospitals evidenced the most rapid decision-making, followed by the LTC facility and lastly the large AC facility with an ICU, where the youngest group of patients on average were cared for. A number of factors may account for this disparity in timing of no-CPR decisions. As indicated, patient gender and patient age were both indicated in the timing for no-CPR decisions. The extensive availability of intensive care and other life supporting technologies in the AC/ICU hospital, as well as a mandate that emphasizes "cure", may also be a factor in the care provided for a significantly younger patient group there. In addition, more males (n=42) than females (n=36) were cared for in the AC/ICU, a gender difference which was not significant (p=.41264) on chi square testing. The unfamiliarity of physician specialists and/or the unit nurses with these AC/ICU patients may have also contributed to this situation. Life support decisions in the AC/ICU hospital appeared to be made between virtual strangers. This situation, however, did not occur for most of the patients in the AC/S hospitals and LTC facility, where

facility staff were familiar with patients and families through repeated admissions and/or lengthy hospitalizations.

The lack of an on-going relationship between patient and health care professionals may also explain why DNR policy adherence was highest in the AC/ICU hospital, and why families were less likely to have potentiated the formation of DNR policies in large AC hospitals. Administrative rules and regulations may be more necessary, and also more adhered to, when "contextualism" (Noddings, 1984) or "relational caring" (Gilligan, 1982) is not prevalent. Contextualism or relational caring may have been a factor in the decision-making for the AC/S and LTC patients, where much greater familiarity between patients, and their nurses and physicians existed. The importance of contextualism or relational caring in care decisions and care intentions has already been indicated in other investigations (Brown & Thompson, 1979; Cooper, 1991; Danis et al., 1991; Jansson & Norberg, 1989; Norberg et al., 1987; Watts et al., 1986).

The influences for no-CPR orders, although numerous and varied, most commonly included family wishes and professional concerns over the outcome of CPR for patients. The professionals involved in no-CPR decisions included select nurses working on the health facility units where these patients were cared for, and the primary physicians. The importance of physicians in decision-making has already been established through numerous investigations (examples: Beaton & Degner, 1990; Davis & Slater, 1989; Ott & Niewiadomy, 1991; Perry et al., 1986; Quill, 1989; Schwartz & Reilly, 1986; Slater, 1987; Vincent, 1990; Wilson, 1991). The personal and professional characteristics of the physicians interviewed in this study could not have been important for end-of-life decisions, since no-CPR orders were written for almost all patients.

The involvement of nurses in life support decisions has not been generally established through previous investigations (see Beaton & Degner, 1990; Wilson, 1991; Wolff et al., 1985). It was not readily apparent from charted entries that nurses were involved in decisions. Interviewed nurses were found however to be very knowledgeable of the no-CPR decision, and they commonly

reported involvement in most no-CPR decisions. The PI learned from interviewing nurses that frequently they had facilitated the no-CPR decision through the physician, having already determined that the family and/or the patient were desiring this decision to be made. Interviewed physicians also commonly reported that nurses (and also families) had been involved in decision-making. Nursing involvement also became evident; as was the case when the PI learned that the newly implemented admission care planning program at the LTC facility only required nurses, as agents of the facility, to obtain a no-CPR or CPR decision from the patient and/or family. This recorded decision would be followed explicitly in the event of patient condition changes. This program had only been in place for one year, which helps explain why no-CPR decisions were still found to have been made after nearly one half of the LTC hospitalizations had elapsed. The importance of nurses in decision-making was also demonstrated by the fact that in 7 cases nurses did not implement CPR in the absence of a no-CPR order.

It should also be emphasized that information from interviewed nurses and physicians, and the charts, frequently indicated that no-CPR decisions were made for patients, when "the patient was at the end of a long and debilitating illness, death was imminent and nothing further could be done". Professional concerns were commonly based on the clinical progression of the patient in response to their illness or aging, and the treatment or hospital care that had been given to mitigate this. An extended life through CPR was not desirable for these patients. The knowledge that CPR may not be effectual for reviving life or for returning the patient to the same cognitive state also contributed to some decisions made by health care professionals. Other studies have similarly established the importance of patient characteristics, including the severity of illness and a poor prognosis, in decisions to limit life support (examples: Brown & Thompson, 1979; Chipman et al., 1981; Dunaway, 1988; Frampton & Mayewski, 1987; Pearlman et al., 1982; Younger, 1985).

Late decision-making, and therefore lack of patient involvement, was frequently associated with mental incompetence. Dying patients, almost

universally, have been found to become cognitively impaired near death (Bruera et al., 1992b). Late decision-making would therefore negate the cognitive ability of patients to be involved. It should be stressed however that it did not appear that the surveyed patients had attempted to voice their life support preferences previous to their end-of-life incompetence. Other studies have similarly established that patients rarely discuss life support with either family members or health care professionals (examples: Bedell & Delbanco, 1984; Bedell et al., 1986; Frampton & Mayewski, 1987; Frankl et al., 1989; Godkin, 1992; Johnson & Justin, 1988; Lo et al., 1986; Perry et al., 1986; Schwartz & Reilly, 1986; Shmerling et al., 1988; Thom, 1988; Vincent, 1990; Wetle et al., 1988). Health care efforts to preserve life, that continue until late into the illness, may negate the possibility of a discussion between health care professionals and patients, or their families, about limiting or stopping treatment.

Patient incompetence contributed to, but does not entirely explain, the finding that family members were commonly involved in decisions to withhold CPR. Only in a few instances were family members legal guardians of the patient, and were therefore a legal proxy for that patient. Family involvement contrasts with the ideal of patient involvement in most DNR policies in Alberta health care facilities. The importance of, and controversy over, family preferences in no-CPR and other end-of-life decisions has already been reported by other researchers (examples: Bedell et al., 1986; Ciocon et al., 1988; Fader et al., 1989; Witte, 1984). It did not appear, however, through the interviews and charts that there was much diversity between health care professionals and families in the decision about whether or not to implement CPR. In the event of patient death, it did not appear that any families, who had been involved in decision-making, wished to have CPR instituted for their family member. One ICU physician indicated that by the time this discussion occurred, most family members had observed treatment to be ineffectual and were aware that death was inevitably near.

These two primary influences for no-CPR decisions indicate a major shift from the two most prevalent influences reported to have potentiated DNR policy (i.e. patient involvement and the decision-making process). While the shifts away from the patient involvement intended by DNR policy and the increased involvement of families in no-CPR decisions were not statistically significant, the shift away from the DNR policy decision-making process was significant. The timing of the no-CPR decision and other process concerns addressed by DNR policies were not commonly found to have contributed to decisions to withhold CPR. No-CPR decisions were again commonly made when "the patient was at the end of a long and debilitating illness, death was imminent and nothing further could be done". No ethical, legal, or other dilemma existed at this point in time for either health care professionals or families, since everything possible had been done to potentiate health and continued life.

In summary, family wishes and professional concerns over the outcome of CPR were the primary influences for no-CPR orders. These influences reflect previously identified influences discussed in the literature review. No support however for considering personal or professional characteristics of physicians (who were found to be part of a team of decision-makers) was derived from the finding that almost all patients had a no-CPR designation. The shift away from the decision-making process, a major influence in the formation of DNR policies, was significant. The age and gender of patients, and the type of health care facility were not generally found influential for no-CPR orders. No-CPR orders were almost universal, as patients approached a certain death. The timing of the no-CPR decision however was found to have been affected by the patient's age, gender, and type of facility. Age, gender, and type of health care facility were also found to be factors in the end-of-life technologies chosen for dying patients.

End-of-Life Technologies and Influences

Only eight (5.8%) of the surveyed charts (7 of which were in the LTC facility and one in the AC/S facility) indicated that patients were not receiving

technological support, that could have potentially sustained life, at the time of death. Frequently, technologies were either introduced or a change in an established technology had taken place in the immediate near-death phase. This near-death phase was observed by the PI to be almost always in the range of one to three days in length. In most cases, additional intermittent or continuous "cure-oriented" (Ajemian, 1992) technologies were discontinued at the time that a near-death determination was made. These technologies were cure-oriented or health promotion oriented, for example: in the LTC facility all patients received annual vaccinations and examinations; while AC patients commonly received daily blood work and other less frequent diagnostic tests, blood transfusions, chemotherapy, and many other individualized technologies. The transition from cure-oriented patient care to dying patient care was very evident, for example in the cases where deaths occurred shortly after a transfer out of the ICU.

Ley's (1989) report of end-of-life care in Britain supports this study's finding that the actual near-death phase is brief, as he indicated that it was common for terminally ill palliative care patients to be hospitalized for two days prior to their demise. This near-death hospitalization occurred despite predominantly community-based palliative care. Lindley-Davis (1991) also found, through reviewing deceased patient's charts, that very noticeable physical signs signal near-death and that these could be recognized by experienced or intuitive persons. This study's finding of professional awareness of near-death directly contradicts research that has concluded that physicians and nurses experience difficulty in recognizing the end-stage of a terminal illness (examples: Bruera, Miller, Kuehn, MacEachern & Hanson, 1992a; Degner, Henteleff & Ringer, 1987; Wilks, 1984). It is possible that health care professionals who have more experience with death and dying may more readily identify near-death signals. For example, Smith (1988) found that nurses working in critical care areas noticed and reacted to signs of impending and certain death. Health care professionals who have been in close, and on-going, proximity with patients may be also more likely to identify the near-death

phase. For example, Brockopp, King, and Hamilton (1991) found significant attitudinal differences between nurses who work with dying patients on a continual basis versus those who rarely encountered dying patients. Part of this difference appeared to be a willingness to accept death as part of the life continuum, and consequently there was an openness to noticing signals of impending death.

Some evidence of family awareness of impending near-death was also noted in this study. For example, a few families in this study were reported to have requested an IV and oxygen for patients, indicating that they believed it would be uncomfortable to die without these technologies. Other researchers have also found that family members become aware of "terminal illness". This awareness was reported to have occurred anywhere between 1 to 1320 days before death (Duff & Hollingshead, cited in Googe & Varricchio, 1981; Hays, 1986; McClusker, 1984). It would be impossible for the near-death phase to extend for weeks or months however. Recognition of terminal illness, as determined in other studies, may actually be an acceptance of the possibility that death would occur at some point in the future. This recognition is a paradigmatic change of thinking in a society where death is rarely spoken of and life is highly valued. A second conceptual shift also appears to occur; that being an awareness that death would be eventuated in the very near future. This near-death recognition negates the work of "hope", an attribute found to be a large component of family members attitudes toward terminal or serious illnesses (examples: McRae & Chapman, 1991; Perakyla, 1991). It may be that no-CPR decisions are commonly, and only, made after either an awareness of terminal illness or impending near-death has occurred.

Despite most patients having a no-CPR order written to direct actions in the event of potential and inevitable death, many end-of-life care decisions were still required when patients neared death. Support for broad-based DNR policies is derived from this finding. Technological intervention in the end-stage dying process, like no-CPR orders, was found to be common practice in all surveyed health care facilities and for almost all patients. Consistency in

technological decision-making only extended to the predominant use of technologies to ease this last phase of life. The use of specific technologies; such as oxygen, IVs, tube feeding, and many "other" technologies, commonly varied in relation to the type of health care facility, as well as the age and gender of patients. The significant differences in technological application associated with gender (i.e. all specific technologies with the exception of oxygen supplementation) are tempered by the large age difference between sampled male and female patients and the observed reduction in technology associated with advanced age. Women, who received less technological intervention at the end-of-life, were older and therefore tended to be more likely candidates for LTC; where few technologies are available and the greatest possibility of dying without technology existed. These three demographic variables are therefore of minimal consequence in comparison to the influences that were found to more directly affect end-of-life technology decisions.

The influences for end-of-life technologies were similar, in all but one regard, to the influences for both no-CPR decisions and DNR policies. The promotion of comfort for patients while dying became a common influence for decision-making. Finding many reports of professional concerns about the comfort of patients while dying therefore introduced a potentially new categorization of influence. The "comfort" influence however was grouped with all "other" influences since it had not been reported as an influence for neither DNR policy formation nor the no-CPR decisions. Statistical comparisons of influences could be more readily made by this grouping of influences.

The two most common influences for end-of-life technologies were: (a) professional concerns (over the possible life or death outcome of care), and (b) all "other" reasons (of which the promotion of patient comfort while dying was the almost universal reason). The patient's wishes or preferences was the least often reported influence for end-of-life technology decisions. Family wishes and the decision-making process were also infrequent influences for end-of-life technology decisions. As indicated, two of these influences did vary in relation to the type of facility. Professional concerns over the outcome of life support

was most prevalent in AC/S facilities, while the decision-making process was only evidenced in the LTC facility.

Influences for dying patient care decisions have been rarely reported in the literature, although the following influences for other end-of-life decisions have been reported: physician preferences, variations in the ethical reasoning of health care professionals, professional and other standards and documents, laws, family preferences, various demographic and clinical patient factors, and autonomous patient preferences. This study found health care professionals made most near-death technology decisions; although in a few cases families were involved. These persons typically aimed to promote comfort for patients while they were dying, a previously unreported influence.

"Comfort" appears to recently have become a taxonomy in health care (Kolcaba, 1991). What actually constitutes "comfort" is currently being debated and investigated (examples: Arruda, Larson & Meleis, 1992; Kolcaba, 1991). This study indicated that professional concerns over patient comfort became predominant in the near-death phase. Until then many, quite often painful or discomforting, diagnostic tests and treatments had been employed in efforts to abate the terminal condition. It is not known however if unconscious near-death patients feel pain. Ferrell, Rhiner, Cohen and Grant's (1991) qualitative study found pain to be a metaphor of progressive illness and death for family members caring for terminally ill cancer victims. This metaphor may extend to the choices made by health care professionals who are required to provide care to hospitalized, potentially "in-pain", near-death patients.

Available health care technologies used in dying patient care are paradoxically potentially life sustaining. Furthermore, they may not even promote comfort of dying persons, but iatrogenically induce discomfort. The use of health care technologies in dying patient care is not supported by the relatively few research investigations that have addressed this controversy (e.g. Andrews & Levine, 1989; Baerg, 1991; Brooker, 1992; Brown & Chekryn, 1989; Bruera, Schoella & MacEachern, 1992c; Constans, Dutertre & Froge, 1991; Cowcher & Hanks, 1990; Dolan, 1983; MacNee, 1992; Musgrave, 1990; Oliver,

1984; Rousseau, 1991; Schmitz, 1991; Stewart & Howard, 1992; Turner, 1987; Winkler, 1987; Zerwekh, 1983). Some surveyed nurses and physicians were aware that the technological assistance provided to dying persons is controversial.

While concerns over patient comfort were widely reported by interviewed health care professionals, it may be that another more subtle influence is a factor in end-of-life decisions. A candid nurse and physician both reported that "at least we felt like we were doing something". This statement indicates that the value of life extends late into the dying process, with health care professionals feeling a duty to sustain life or at least be actively "doing something". Promotion of patient comfort as an influence for implementing near-death technologies may support health care professionals who are attempting to adjust their presumed professional cure-oriented roles to dying patient care.

The increased predominance of health care professionals and a further reduction of patient influence in this last phase of care planning was demonstrated in this study. The use of near-death technologies was commonly based on professional concerns that patients die comfortably. It would seem that near-death patient care constitutes a virtually unknown field for laypersons, which then potentiates the role of health care professionals in making near-death technological decisions. The influence of professional concerns over the outcome of life support use, which was the most common influence for both end-of-life decisions, also indicates the predominance of professionals in end-of-life patient care. Patient and family involvement in decision-making became less and less a probability as death approached.

It is possible that this disengagement by patients and families is intentional. Hull's (1989) research of home hospice care indicated that family members, attempting to cope with the situation, found it necessary to exit the caregiving role before their relative's death. Ley's (1989) report also indicated that the caregiving role is avoided, as two thirds of palliative care deaths, despite an extensive home palliative care service (Bergen, 1991; Seale, 1992),

occurred in British hospitals. Hjelmerus (1987) similarly indicated that 60 percent of Swedish home palliative care patients actually died in hospital. Chappell (1992), a Canadian sociologist, believes informal caregiver burden may be a large factor in the AC hospitalizations of terminally ill Canadians. Watson and Maxwell (1977) alternatively argued that dying persons are segregated in hospitals due to a societal abhorrence with death. Societal expectations about health care and fears about discomfort while dying may also have created the belief that hospitalization is superior to home deaths. Eight five percent of Canadians now die in health care facilities, an incremental increase indicated by a report that 20 years ago only 70 percent of deaths occurred in hospitals (Latimer, 1991). It could also be that the passive acceptance of death, as would be indicated by home deaths, is unacceptable in health care circles and society. The medicalization of dying, which propagates and is propagated by the belief that health care interventions can promote a pain-free death (Chappell, 1992), may also be largely responsible for hospitalization as well as near-death technology choices. The most effective setting for palliative care and the most needy recipients of palliative care have yet to be established (Gotay, 1987).

The deaths of surveyed patients in the LTC facility could be explained by the finding of a very long length of stay. The LTC facility had become home to those persons who passed away there. Despite Canadian health care facilities having become the most common site of death, the majority of surveyed AC and LTC facilities (n=72, 53.3%) had no mention of death or dying in their written organizational mandate or philosophy (only 39.3% did). Seventy of the surveyed facilities (51.9%), however, had a nursing philosophy of care that did refer to dying (31.9% did not). This common organizational oversight of death and dying may also help to explain why there are only 767 palliative care beds in the whole of Canada (Ajemian, 1992), when almost 200,000 Canadians die annually (Statistics Canada, 1991). The oversight of death and dying may also help to explain why most patients in this study were assessed by the PI to have

received primarily "cure-oriented" care until a matter of hours or days before their demise.

Many questions are raised by the finding of extensive technological assistance to near-death patients. The influences for technological assistance of dying are not at all evident despite five influences being indicated through this survey. As also indicated (in the results section), the prevalence and rank ordering of end-of-life technology decision influences differed from no-CPR decision influences. The most common influences for DNR policies were also observed to be the two least common influences for end-of-life technologies. Very real shifts in the rank order and prevalence of influences for DNR policies, no-CPR decisions, and for end-of-life technologies therefore occurred. No statistically significant differences however were determined between influences for end-of-life technology decisions and DNR policies, which may have largely been due to the analysis of variance test chosen for this comparison. The analysis of variance test measures differences in means, and not differences in rank ordering of influences.

The infrequency of influences for end-of-life technologies may have also contributed to one of the significant differences found when the influence "professional concern over life support outcomes" was compared, again using analysis of variance testing, between end-of-life technologies and no-CPR decisions. No change in rank order had occurred; since "professional concerns" was the most common influence for both practice decisions. Professional concerns over the outcome of life support would understandably be reported less often when end-of-life technology decisions were made. At this point in time there was common recognition that death would occur in the near future, regardless of any ongoing technologies chosen to comfort the patient.

Three additional significant differences in end-of-life technology and no-CPR decision influences were found. The influence of "patient's wishes" changed from being reported third most often in no-CPR decisions to being the least mentioned influence in end-of-life technology decisions. The influence of the "family" also became much less prevalent after the no-CPR decision had

been made. In contrast, the "other" influence was the most uncommon category of influences for no-CPR decisions, but this category became the second most commonly reported influence for technology decisions. Only the decision-making process influence was not found to have varied significantly between the two end-of-life decisions. For both no-CPR and end-of-life technology decisions, the decision-making process influence was reported relatively infrequently.

It is also interesting that only one significant difference between no-CPR decisions and DNR policy influences was found. The decision-making process was the most prevalent influence for DNR policies and one of the least frequently mentioned influences for no-CPR decisions. It is understandable that a significant difference was found, since policies address practices generally without consideration for the context of decision-making. The practice of leaving decision-making until the patient can no longer be involved represents a tradition based on societally derived expectations and roles of health care providers.

Conceptual Framework

The conceptual framework provided a delimiting guide for assessing and comparing the influences for DNR policies, and end-of-life treatment and non-treatment decisions. DNR policies were found to have been developed as a consequence of numerous influences; at various macro, meso, and micro levels. It was not always evident what level these influences represented. The organizational concern or meso level influence of ensuring a "good" decision-making process that involved the patient in life support decisions was evident in DNR policies. To a lesser extent the macro-level right of patients to be involved in decision-making (Storch, 1982) was also primarily important.

No-CPR orders and end-of-life technology decisions also appeared to be influenced by a plethora of largely similar macro, meso and micro level influences. The organizational concern over a "good" decision process that involved the patient in decision-making was generally replaced by family and

health care professional influences that were micro-level (individual) and macro-level (societal) in nature. An open and interactive "system" of health care facilities is readily identifiable.

Summary

The incidence of DNR policies, no-CPR orders, and end-of-life technological interventions in Alberta AC and LTC facilities were described. Most accredited health care facilities in Alberta have developed DNR policies; with approximately one half of DNR policies addressing more than just the CPR or no-CPR decision. Withholding CPR, as well as technological intervention in the end-stage dying process, were found to be common health care practices. The influences for these DNR policies, no-CPR decisions, and end-of-life technology decisions tended to be numerous. Influences were grouped into five categories, with changes in the predominance of these influences being observed. DNR policies were influenced primarily by an organizational need to ensure timely decision-making that would involve patients in decisions. No-CPR orders were written for most patients after a considerable portion of their hospitalization had elapsed, and it was evident to families and health care professionals that attempts to prevent death were inappropriate. The promotion of comfort through technological interventions then became a goal primarily shared by physicians and nurses for these dying patients.

Chapter VI
Conclusions and Implications

Overview of Chapter

The findings of this study are summarized into three sets of conclusions and implications; those associated with DNR policies, with no-CPR decisions and decision-making practices, and with end-of-life technological decisions and decision-making practices. Implications are specified for practice, research, and education.

DNR Policies

Conclusions. DNR policies were reported by the majority of accredited health care facilities in Alberta. There was no relationship between DNR policy existence and the type of facility, nor the presence of an ICU and related intensive care technologies. The size of the facility did influence DNR policy formation, with more policies being found in larger facilities. The trend to formulate DNR policies originated in 1984, synonymous with the publication of the Joint Statement. Most DNR policies were developed in the 1990s, however. A second more recent trend of broadly focused resuscitation policies was also evident, as nearly one-half of the policies aimed to rationalize decisions about a wide variety of other potentially life sustaining interventions. An organizational concern over the ability for multiple life supporting interventions to prolong life and delay inevitable death was demonstrated through these policies.

Although a range of policy influences was found, most policies aimed to ensure the involvement of patients in an optimal and standardized decision-making process. The purpose of most policies was therefore the basis for their development. Almost all SNAs believed that their facility's DNR policy was synonymous with clinical practice. Surveys of four facilities (representing the three main types of health care facilities) however indicated that DNR policies were commonly not fully adhered to, and that in almost one third of cases they were not at all implemented. Problems generally stemmed from late decision-

making that excluded the patient from end-of-life decisions. DNR policies appeared to be commonly ineffectual for governing practice.

Implications. The rising prevalence of DNR policies, in conjunction with concerns over their actual implementation and effect on decision-making and clinical practice, bring a number of implications for practice, education, and research into focus.

1. Public and professional education about the prevalence of DNR and related policies in Alberta health care facilities is required. It is important that misconceptions about using or withholding CPR, and other life supports, be eliminated. Certainly, there is much organizational support for limiting life support. It is also obvious that limiting life support is acceptable to health care professionals and members of the public.
2. Due to finding minimal policy adherence, all administrators in health care facilities that currently have a DNR policy are urged to undertake an internal DNR policy review. This review should determine to what degree nurses and physicians in that facility are knowledgeable of the DNR policy, and therefore what presumed effect this policy has on decision-making and patient outcomes. Following this evaluation, health care administrators will then need to decide on retaining, revising, or discontinuing the DNR policy. If retained, adherence to policy should be stressed, since lack of adherence to organizational policy places health care facilities in legal and ethical jeopardy. Additional education of nurses and physicians about the policy may therefore be essential. Improved policy implementation may also require the development of a separate "DNR" chart form to improve recording practices and perhaps guide the DNR decision-making. If the DNR policy is discontinued then an alternative means of optimizing decision-making must be sought.
3. An investigation of decision-making practices, end-of-life care and the influences for treatment and non-treatment decisions in facilities that did not report a DNR policy would be beneficial. This investigation would

pindicate whether end-of-life care decisions, decision influences, and decision processes in these facilities differ from facilities that do have a DNR policy. A determination of whether differences are beneficial or not could then be made. DNR policy development may be supported by these findings. Alternatively, this study may indicate that DNR policies are not essential or even beneficial for end-of-life decisions and patient outcomes.

4. Despite the continuing debate over whether DNR policies are essential or not, it is obvious that enhancement of patient self-determination is urgent. The infrequency of patient involvement in end-of-life decisions observed in this study indicates a need for research, education, and change in practice. Even if the ATD legislation is not implemented in Alberta, the quality improvement and risk management movement (as described by DesHarnais, McHahon & Woblewski, 1991; Jones, 1992 and others) will require changes in end-of-life decision processes. In addition to public education aimed at promoting self-determination, it will be necessary for individual patients to have their right of self-determination fostered by health care professionals. Health care professionals will need to educate patients or their surrogate health care agents to a greater degree than ever before. The ability of health care professionals to educate effectively may need to be assessed and, in some situations, improved through remedial continuing education.
5. If the ATD legislation is enacted by the Alberta legislature, each health care facility in Alberta will quickly need to review and, in some cases, revise their DNR policy. Most facilities will need to make changes in the method in which the life support preferences of patients are determined, and then used to formulate care decisions. An investigation of the effect of ATD legislation on DNR policies and end-of-life patient care decisions would also be highly beneficial for other provinces contemplating ATD legislation.
6. Misconceptions of SNAs over whether or not DNR policies are implemented indicate that additional health care policy evaluation studies are needed to describe and to evaluate the role of policy in health care organizations.

7. Health care administrators and professional associations are encouraged to review their philosophies and/or mandates. The absence of reference to death and dying in these documents would indicate that a process of revision is required. This process would assist in raising the consciousness of health care professionals to a broader definition of health and illness, and also bring about a more accurate understanding of the current and future needs of an aging Canadian population.
8. Finally, additional and perhaps ongoing surveys of DNR policies and life support practices are required to inform the public, health care professionals, and health care organizations of the trends and changes occurring both in life support and in the processes used to rationalize their use. These trends and changes may extend to Alberta facilities that are not currently accredited and to health care facilities outside of Alberta. Surveys should therefore not be limited to those facilities that meet accreditation standards.

No-CPR Decisions and Decision-Making Practices

Conclusions. CPR was almost universally withheld. Most deaths, investigated in this study, occurred at the end of a long and progressively debilitating illness. The recognition of a certain and impending death appeared to lead to the consensual no-CPR decisions made by health care professionals and family members. Decision-making practices, however, did not facilitate either the direct or indirect involvement of the patient. No-CPR decisions were usually made late in the course of hospitalization, and treatment efforts to that point had been incapable of restoring health or maintaining life. Withholding CPR did not then create a legal or ethical dilemma for health care professionals or family members, as everything possible appeared to have been done to restore health and prevent death.

Implications. The finding of an almost universal practice of withholding CPR from dying inpatients brings a number of implications for practice, education, and research to focus.

1. All health care professionals, members of the public, and persons involved in health policy and planning should become aware, through educational means, of the prevalence of no-CPR decisions. This information may help to allay legal or other fears, and ethical dilemmas over whether or not to withhold CPR. This information could also contribute to the discontinuation of yearly CPR training for all health care professionals. These programs are costly, and do not appear to be needed on such a wide scale. Health care facilities may instead concentrate CPR training to those personnel employed in departments where is it more likely that unexpected deaths occur, for example the emergency department.
2. Despite the prevalence of no-CPR orders, the variable timing of no-CPR decisions in the different types of health care facilities, and between patients of different gender and age, indicates a need for further study and also for immediate attention of health care professionals to this problem. It may be that age-biased treatment decisions are a common, but largely overlooked, outcome of being old. Ageism is a particular concern, since reviewed charts revealed that young patients frequently had health conditions more severe and intractable than most elderly non-hospitalized Albertans. Sexism as an influence in health care decisions may also be prevalent and, if so, should be likewise addressed through research, policy, and education.
3. Additional focused investigations of the impact of no-CPR decisions on subsequent patient care decisions are also indicated by this study's finding that the no-CPR order was generally followed by a reduction in aggressiveness of treatment. It should be stressed however, that the no-CPR decisions were generally made when it was evident that patients would die in the near future. Whether earlier no-CPR decisions tend to limit treatment efforts is of interest, especially in light of the emerging

living will/ATD legislation where earlier no-CPR decisions will be made. Investigations are also required of the treatments used to reverse or mitigate chronic and end-stage illnesses. Patient outcomes, cost of interventions, and the Canadian society's ability to provide health care are of particular importance for an ethical and cost-benefit appraisal of health care practices.

4. In light of the infrequency of patient involvement in no-CPR decisions, health care facilities should consider the development of programs, such as the LTC admission care planning meetings, to facilitate patient involvement in no-CPR and other health care decisions. Another beneficial organizational change may be the routine admission surveillance of patients for written living wills/ATDs, or verbal life support preferences and wishes. Earlier and non-urgent discussions and decisions are required if patient informed decisions are to become standard practice.
5. Patient care delivery changes, such as case management (Bergen, 1992) may also be needed to improve the timing and appropriateness of end-of-life decisions. With health care specialization appearing to be a continuing trend, there is a need to improve continuity in patient-professional relationships (particularly in large AC hospitals). Patients need not be treated in isolation within each facility and by each health care professional. An emphasis on increasing the on-going and indepth nature of involvement of health care professionals with patients and their families is essential.
6. Adherence to organizational rules such as those presented by DNR policies, and the perpetuation of current health care practices where all possible curative and restorative treatment is routinely offered to patients, negates the development of the ability for health care professionals to reason ethically and to plan care under resource allocation considerations. These concerns appear to be particularly relevant in large specialized hospitals where organizational rules appear to be more prevalent and more closely followed. Continued emphasis on both ethical reasoning and resource

allocation in the fields of research, entry-level professional education programs, and continuing education courses is indicated.

End-of-life Technology Decisions

Conclusions. The use of one or more available health care technologies, during the last phase of the end-of-life period, was found to be common practice. The chosen technologies were primarily intended by health care professionals to promote patient comfort. While technologies were individualized to each patient, a wide variation in technology use was observed. The age and gender of the patient, and the type of health care facility generally influenced near-death technological decisions. Oxygen supplementation, the most common intervention, was the only intervention not differentiated by gender. Decisions to implement end-of-life technologies, like those of the no-CPR decision, were generally made late in the course of hospitalization. Patients again were rarely involved, either directly or indirectly, in end-of-life technology decisions. Unlike with the no-CPR decision-making process, family preferences became an infrequent influence in end-of-life technology decisions.

Despite having determined the charted and reported influences for end-of-life technologies, it is not really evident why many of these technologies were used. Technologies were potentially life sustaining and may have actually extended the process of dying. Furthermore, these technologies may have introduced additional pain and suffering. Continued widescale professional difficulties over making end-of-life patient care decisions were therefore indicated. The value of life, coupled with an established pattern of technological dependence in health care, suggest these difficulties will continue.

Implications. Six main implications of the findings associated with end-of-life technology decisions and decision-making practices are apparent.

1. Qualitative methods of research are required to elicit elusive influences for end-of-life technology decisions.

2. The benefits in using specific technologies as comfort measures near death also need to be substantiated or refuted through research. The impact of IVs, oxygen, and other technologies on the dying process is not currently known. In the interim, all health care professionals should become aware of the controversy over technological support of dying persons. It is important that nurses and physicians be informed of this controversy, since both groups of professionals are involved in decision-making.
3. This study's finding that no-CPR decisions and end-of-life technology decisions are largely based on the presumed effect of life support, lends credence to a proposed change of research focus and treatment efforts; namely patient outcomes (see Mahrenholz, 1991; McCormick, 1992 for example). Consequentialism (Beauchamp & Childress, 1989), the founding of decisions on expected outcomes, therefore appears to be a trend which will or may already have supplanted the presumed predominant deontological or duty-oriented care of patients. Health care professionals need to be informed that a paradigmatic shift in health care decision-making is occurring. Further investigations to validate and chart this shift are also required.
4. The differential use of end-of-life technologies based on age and gender should also be investigated, and information conveyed to health care professionals and health facility administrators. This information will hopefully begin changes in practice which will address the gender and age biases that were indicated in this study.
5. The practice of palliative care in acute-care hospitals and long-term care facilities also bears further investigation. While the most appropriate site for end-of-life care has been the subject of some investigation, a more grounded approach to determining why dying persons are hospitalized is suggested. Palliative care could, and perhaps should, occur in the home. Community-based palliative care programs would need to expand, and public education about this shift in health care delivery would then be required. Although palliation may never become entirely community

based, lengthy end-of-life hospitalizations could, and should, be eliminated.

6. Finally, much more research in all areas of death and dying is urgently required. As the population ages and sophisticated health care technologies become even more capable of sustaining life, death and dying must be addressed.

Summary

This chapter has summarized the findings and introduced implications of this study. In particular, the majority of health care organizations were found to have developed DNR policies, a recent trend that appears as if it will continue into the near future. These policies were primarily developed, from an organizational perspective, to optimize a decision-making process. Involving the patient in decision-making was a secondary goal. DNR policies were not generally found to have accomplished their primary purposes, however. No-CPR and end-of-life technology decisions tended to be made late, after a patient was near-death and incapable of involvement in care decisions. Family members and health care professionals tended to make no-CPR decisions, decisions which appeared to be largely based on the futility of CPR for that patient. CPR was withheld from almost every patient. Should ATD legislation be enacted in Alberta, the focus of some DNR policies and most health care practices will need to change. Ensuring that the patient, or their designated health care agent, is the primary decision-maker in decisions to either withhold or implement all forms of life support will need to be the primary change.

Most patients died with at least one potentially life sustaining technology in operation. End-of-life technology decisions were primarily made by health care professionals who were attempting to ensure patient comfort during the end-stage dying process. Patients and families were rarely involved in these end-of-life technology decisions. The prevalence of technologies, and their diversity along gender, age, and health care facility biases, indicates that end-of-life care is an undeveloped practice. Health care facilities may have already recognized

a need to optimize end-of-life technology decisions, as almost one half of DNR policies in Alberta currently address life support interventions in addition to the CPR/no-CPR decision. Many research and educational needs are apparent however in end-of-life patient care and decision-making. The greatest needs pertain to the promotion of patient comfort during a recognizable and inevitable end-stage dying process.

Overall, the influences for DNR policies were found to be relatively similar to the influences for no-CPR decisions and for end-of-life technology decisions. The prevalence of these influences varied, however. In particular, the policy goal of patient autonomy in an optimized decision-making process, did not appear to be achieved in practice. End-of-life technology influences tended to vary much more, however, in relation to the influences for no-CPR decisions. A professional goal of ensuring patient comfort during the final stage of dying became the major influence after life preservation efforts had failed.

References

Abbey, J. C. (1978). Concepts and principles. In A. M. Putt (Ed.), General Systems Theory Applied to Nursing (pp. 9-16). Boston: Little, Brown & Co.

Ackoff, R. L. (1974). Redesigning the future: A systems approach to societal problems. New York: John Wiley.

Ackerman, T. (1983). Experimentalism in bioethics research. Journal of Medicine and Philosophy, 16(3), 235-258.

Addison, M. (1991). Advance directives - a physician's view. Health Law Review, 1(1), 9-18.

Aidroos, N. (1986). Nurses' response to doctors' orders for close observation. Canadian Journal of Psychiatry, 31, 831-833.

Ajemian, I. C. (1992). Hospitals and health care facilities. Journal of Palliative Care, 8(1), 33-37.

Akerlund, B. M., & Norberg, A. (1985). An ethical analysis of double bind conflicts as experienced by care workers feeding severely demented patients. International Journal of Nursing Studies, 22, 207-216.

Alberta Law Reform Institute. (1991). Advance directives and substitute decision-making in personal health care. Edmonton, AB: Author.

Alberta Senior Citizens Secretariat. (1989). Older Albertans. Edmonton, AB: Author.

Alemaychu, E., Molloy, D. W., Guyatt, G. H., Singer, J., Penington, G., Basile, J., Eiseman, M., Finucane, P., McMurdo, M. E. T., Powell, C., Zelmanowicz, A., Puxty, J., Power, C., Vitou, L., Levenson, S. A., & Turpie, I. D. (1991). Variability in physicians' decisions on caring for chronically ill elderly patients: An international study. Canadian Medical Association Journal, 144(9), 1133-1138.

Anderson, M., Gladue, S., Laurie, M., Skotniski, E., & Tramer, D. (1991). The living will issue. The Canadian Nurse, 87(10), 37-39.

Andrews, M. R., & Levine, A. M. (1989). Dehydration in the terminal patient: Perception of hospice nurses. The American Journal of Hospice Care, 6(1), 31-34.

Aroskar, M. A. (1987). The interface of ethics and politics in nursing. Nursing Outlook, 35(6), 268-273.

Arruda, E. N., Larson, P. J., & Meleis, A. I. (1992). Comfort. Immigrant Hispanic cancer patients' views. Cancer Nursing, 15(6), 387-394.

Ashby, W. R. (1972). Systems and their informational measures. In G. J. Klir (Ed.), Trends in General Systems Theory (pp. 94-100). New York: John Wiley & Sons.

Baerg, K. L. (1991). Effects of dehydration on the dying patient. Rehabilitation Nursing, 16(3), 155-156.

Beaton, J. I., & Degner, L. F. (1990). Life & death decisions: The impact on nurses. The Canadian Nurse, 86(3), 18-22.

Beauchamp, T. L., & Childress, J. F. (1979). Principles of biomedical ethics. New York: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (1989). Principles of biomedical ethics (3rd ed.). New York: Oxford University Press.

Bedell, S. E., & Delbanco, T. L. (1984). Choices about cardiopulmonary resuscitation in the hospital. When do physicians talk with patients? The New England Journal of Medicine, 310(17), 1089-1093.

Bedell, S. E., Delbanco, T. L., Cook, E. F., & Epstein, F. H. (1983). Survival after cardiopulmonary resuscitation in the hospital. The New England Journal of Medicine, 309(10), 569-576.

Bedell, S. E., Pelle, D., Maher, P. L., & Cleary, P. D. (1986). Do-not-resuscitate orders for critically ill patients in the hospital. How are they used and what is their impact? JAMA, 256(2), 233-237.

Bergen, A. (1991). Nurses caring for the terminally ill in the community: A review of the literature. International Journal of Nursing Studies, 28(1), 89-101.

Bergen, A. (1992). Case management in community care: Concepts, practices and implications for nursing. Journal of Advanced Nursing, 17(9), 1106-1113.

Berman, P. (1978). The study of macro- and micro-implementation. Public Policy, 26(2), 157-184.

Bexell, G., Norberg, A., & Norberg, B. (1980). Ethical conflicts in long-term care of aged patients. Analysis of the tube-feeding decision by means of a teleological ethical model. Ethics in Science and Medicine, 7, 141-145.

Birnbaum, D., Schulzer, M., Mathias, R. G., Kelly, M., & Chow, A. W. (1990). New infection control strategies in acute care. Dimensions-in-Health-Service, 67(4), 26-29.

Bland, M. (1987). An introduction to medical statistics. Oxford, England: Oxford University Press.

Blum, L. A. (1988). Gilligan and Kohlberg: Implications for moral theory. Ethics, 98, 472-491.

Boulding, K. E. (1969). General systems theory - the skeleton of science. In W. Buckley (Ed.), Modern Systems Research for the Behavioral Scientist (pp. 3-10). Chicago: Aldine Pub. Co.

Bolton, M. A. (1989). Who can let you die? Canadian Journal on Aging, 8(3), 238-243.

Brink, P. J., & Wood, M. J. (1983). Basic steps in planning nursing research. From question to proposal. Monteray, CA: Wadsworth Health Sciences Division.

Brockopp, D. Y., King, D. B., & Hamilton, J. E. (1991). The dying patient: A comparative study of nurse caregiver characteristics. Death Studies, 15(3), 245-258.

Brooker, S. (1992). Dehydration before death. Nursing Times, 88(2), 59-62.

Brown, P. & Chekryn, J. (1989). The dying patient and dehydration. The Canadian Nurse, 85(5), 14-16.

Brown, N. K., & Thompson, D. J. (1979). Nontreatment of fever in extended-care facilities. The New England Journal of Medicine, 300, 1246-1250.

Bruera, E., Miller, M. J., Kuehn, N., MacEachern, T., & Hanson, J. (1992a). Estimate of survival of patients admitted to a palliative care unit: A prospective study. Journal of Pain and Symptom Management, 7(2), 82-85.

Bruera, E., Miller, L., McCallion, J., Macmillan, K., Krefting, L., & Hanson, J. (1992b). Cognitive failure in patients with terminal cancer: a prospective study. Journal of Pain and Symptom Management, 7(4), 192-195.

Bruera, E., Schoella, T., & MacEachern, T. (1992c). Symptomatic benefit of supplemental oxygen in hypoxemic patients with terminal cancer: The use of the N of 1 randomized controlled trial. Journal of Pain and Symptom Management, 7(6), 365-368.

Canadian Council on Health Facilities Accreditation. (1992). Accreditation in Canada. Ottawa: Author.

Canadian Hospital Association. (1990). Directory of long-term care centres in Canada. Ottawa: Author.

Canadian Hospital Association. (1991). Canadian Hospital Directory. Ottawa: Author.

Carey, R. G., & Posavac, E. J. (1978). Attitudes of physicians on disclosing information to and maintaining life for terminal patients. Omega, 9(1), 67-77.

Carse, A. L. (1991). The 'voice of care': Implications for bioethical education. The Journal of Medicine and Philosophy, 16, 5-28.

Cavallo, R. (Ed.). (1982). Systems methodology in social science research. Recent developments. Boston: Kluwer * Nijhoff Publishing.

Chappell, N. L. (1992). Social support and aging. Toronto: Butterworths.

Chipman, C., Adelman, R., Sexton, G. (1981). Criteria for cessation of CPR in the emergency department. Annals of Emergency Medicine, 10(1), 11-17.

Ciocon, J. O., Silverstone, F. A., Graver, L. M., & Foley, C. J. (1988). Tube feeding in elderly patients. Indications, benefits, and complications. Archives of Internal Medicine, 148, 429-433.

Constans, T., Dutertre, J. P., & Froge, E. (1991). Hypodermoclysis in dehydrated elderly patients: Local effects with and without hyaluronidase. Journal of Palliative Care, 7(2), 10-12.

Cooper, M. C. (1991). Principle-oriented ethics and the ethic of care: A creative tension. Advances in Nursing Science, 14(2), 22-31.

Council Report. Council on Ethical and Judicial Affairs, American Medical Association. (1991). Guidelines for the appropriate use of do-not-resuscitate orders. JAMA, 265(14), 1868-1871.

Cowcher, K., & Hanks, G. W. (1990). Long-term management of respiratory symptoms in advanced cancer. Journal of Pain and Symptom Management, 5(5), 320-330.

Crane, D. (1975). Decisions to treat critically ill patients: A comparison of social versus medical considerations. Milbank Memorial Fund Quarterly, 53, 1-33.

Crocker, E. (1987). In my opinion...Top ten "no cost" features. Canadian Health Care, 15(4), 233-234.

Dalton, M., Blondeau, J., Dockerty, E., Fanning, C., Johnston, L., LeFort-Jost, S., & MacDonald, S. (1992). Compliance with a nonrecapping needle policy. Canadian Journal of Infection Control, 7(2), 41-44.

Danis, M., Southerland, L. I., Garret, J. M., Smith, J. L., Hielema, F., Pickard, C. G., Egner, D. M., & Patrick, D. L. (1991). A prospective study of advance treatment directives for life-sustaining care. The New England Journal of Medicine, 324(13), 882-888.

Davidson, K. W., Hackler, C., Caradine, D. R., & McCord, R. S. (1989). Physicians' attitudes on advance directives. JAMA, 262(17), 2415-2419.

Davis, A. J., & Slater, P. V. (1989). U.S. and Australian nurses' attitudes and beliefs about the good death. IMAGE: Journal of Nursing Scholarship, 21(1), 34-39.

Deacon, J. & Came, B. (1991, December 9). The right to die. A court hears a woman's desperate plea. Maclean's, p. 49.

Degner, L. F., Henteleff, P.D., & Ringer, C. (1987). The relationship between theory and measurement in evaluations of palliative care services. Journal of Palliative Care, 3(2), 8-13.

DesHarnais, S., McMahon, L. F., & Wroblewski, R. (1991). Measuring outcomes of hospital care using multiple risk-adjusted indexes. Health Services Research, 26(4), 425-443.

Dolan, M. B. (1983). Another hospice nurse says. Nursing 83, 13(1), 51.

Dougherty, C. M. (1990). Recovery following sudden cardiac death during hospitalization. Unpublished doctoral dissertation, University of Washington, Seattle, Washington, U.S.A.

Dunaway, P. (1988). Decisions to discontinue intensive therapy, influencing factors and approaches to decision-making. Intensive Care Nursing, 4, 106-111.

Dundas, S., Young, O., & Davis, L. (1988). Charting behaviours of psychiatric nurses. AARN Newsletter, 44(7), 10-14.

Dunn, W. (1984). An introduction. Public policy analysis. Englewood Cliffs, NJ: Prentice-Hall.

Edwards, B. S. (1990). Does the DNR patient belong in the ICU? Critical Care Nursing Clinics of North America, 2(3), 473-480.

Enderlin, A., & Wilhite, M. J. (1991). Establishing incidence and administrative protocols for do not resuscitate orders. Journal of Gerontological Nursing, 17(3), 12-16.

Evans, A. L., & Brody, B. A. (1985). The do-not-resuscitate order in teaching hospitals. JAMA, 253(15), 2236-2239.

Fader, A. M., Gambert, S. R., Nash, M., Gupta, K. L., & Escher, J. (1989). Implementing a "do-not-resuscitate" (DNR) policy in a nursing home. Journal of the American Geriatrics Society, 37(6), 544-548.

Farber, N. J., Bowman, S. M., Major, D. A., & Green, W. P. (1984). Cardiopulmonary resuscitation (CPR). Patient factors and decision making. Archives of Internal Medicine, 144, 2229-2232.

Ferrell, B. R., Rhiner, M., Cohen, M. Z., & Grant, M. (1991). Pain as a metaphor for illness: impact of cancer pain on family caregivers. Part 1. Oncology Nursing Forum, 18(8), 1303-1309.

Fowler, F. J. (1984). Survey research methods. Beverly Hills, CA: Sage Publications.

Frampton, M. W., & Mayewski, R. J. (1987). Physicians' and nurses' attitudes toward withholding treatment in a community hospital. Journal of General Internal Medicine, 2, 394-399.

Frankl, D., Oye, R. K., & Bellamy, P. E. (1989). Attitudes of hospitalized patients toward life support: A survey of 200 medical inpatients. The American Journal of Medicine, 86, 645-648.

Fry, S. T. (1989). The role of caring in a theory of nursing ethics. Hypatia, 4(2), 88-103.

Fry, S. T. (1991). A theory of caring: Pitfalls and promises. In D. A. Gaut & M. M. Leininger (Eds.), Caring: The compassionate healer (pp. 161-172). New York: National League for Nursing.

Gilligan, C. (1982). In a different voice: Psychological theory and women's development. Cambridge: Harvard University Press.

Goddard, H. (1988). Voluntary euthanasia declaration goes step beyond living will. Canadian Medical Association Journal, 139, 246.

Godkin, M. D. (1992). Cardiopulmonary resuscitation: Knowledge, attitudes, opinions of older adults in acute care and long-term care settings. Unpublished master's thesis, University of Alberta, Edmonton, Alberta.

Goff, J. S. (1992). Percutaneous gastrostomy and jejunostomy: Lessons from the first decade. Canadian Journal of Gastroenterology, 6(3), 149-154.

Googe, M. C., & Varricchio, C. G. (1981). A pilot investigation of home health care needs of cancer patients and their families. Oncology Nursing Forum, 8(4), 24-28.

Gotay, C. C. (1987). Research issues in palliative care. Journal of Palliative Care, 3(2), 24-31.

Government of Canada. (1988). Canada's seniors. A dynamic force. Canada: Minister of Supply and Services.

Grammatik Windows Version 2.0. (1991). Grammatik windows, the easiest way to improve your writing. Washington, DC: Reference Software International.

Gray, W. (1969). General theoretical considerations. Introduction. In W. Gray, F. J. Duhl, & N. D. Rizzo (Eds.), General Systems Theory and Psychiatry (pp.1-6). London: J & A Churchill Ltd.

Gray, W., Duhl, F. J. & Rizzo, N. D. (Eds.) (1969). General Systems Theory and Psychiatry. London: J & A Churchill Ltd.

Gray, W., & Rizzo, N. D. (1969). History and development of general systems theory. In W. Gray, F. J. Duhl, & N. D. Rizzo (Eds.), General Systems Theory and Psychiatry (pp.7-32). London: J & A Churchill Ltd.

Gregory, L. (1987). Health care managers' values and decision making. In G. R. Anderson and V. A. Glesnes-Anderson (Eds.), Health care ethics. A guide for decision makers (pp. 34-46). Rockville, MA: Aspen Publishers, Inc.

Guarino, K. S., & Antoine, M. P. (1991). The case of Nancy Cruzan: The supreme court's decision. Critical Care Nurse, 11(1), 32-40.

Hackler, J. C., & Hiller, F. C. (1990). Family consent to orders not to resuscitate. JAMA, 264,(10), 1281-1283.

Hall, A. D., & Fagen, R. E. (1969). Definition of system. In W. Buckley (Ed.), Modern Systems Research for the Behavioral Scientist (pp. 81-92). Chicago: Aldine Pub. Co.

Hays, J. C. (1986). Hospice policy and patterns of care. IMAGE: Journal of Nursing Scholarship, 18(3), 92-97.

Hilfinker, D. (1983). Allowing the debilitated to die: Facing our ethical choices. New England Journal of Medicine, 308, 716-719.

Hiller, M. D. (1987). Ethical decision making and the health administrator. In G. R. Anderson and V. A. Glesnes-Anderson (Eds.), Health care ethics. A guide for decision makers (pp. 330-349). Rockville, MA: Aspen Publishers, Inc.

Hjelmerus, L. (1987). Care of the dying: Present situation in Sweden. The Hospice Journal, 3(1), 91-95.

Hodgetts, R. M., & Wortman, M. S. (1980). Administrative policy. Text and cases in strategic management. New York: John Wiley & Sons, Inc.

Honan, S., Helseth, C. C., Bakke, J., Karpiuk, K., Krsnak, G., & Torkelson, R. (1988). Perception of "no code" and the role of the nurse. The Journal of Continuing Education in Nursing, 22(2), 54-61.

Houston, B. (1989). Prolegomena to future caring. In M. M. Brabeck (Ed.), Who cares? Theory, research, and educational implications of the ethic of care (pp. 84-100). New York: Praeger.

Huggins, E. A., & Scalzi, C. C. (1988). Limitations and alternatives: Ethical practice theory in nursing. Advances in Nursing Science, 10(4), 43-47.

Hull, M. M. (1989). A family experience: Hospice supported home care of a dying relative. Unpublished PhD dissertation, The University of Rochester, U.S.A.

In Brief. (1991). The USA congress adopts a firm line on living wills. The Bioethics Bulletin, The University of Alberta, 3(1), 5.

Jansson, L., & Norberg, A. (1989). Ethical reasoning concerning the feeding of terminally ill cancer patients. Cancer Nursing, 12(6), 352-358.

Jenkins, W. I. (1978). Policy analysis. A political and organizational perspective. London: Martin Robertson & Co., Ltd.

Johnson, R. A., & Justin, R. G. (1988). Documenting patients' end-of-life decisions. Nurse Practitioner, 13(6), 41-52.

Joint Statement on Terminal Illness. (1984). A protocol for health professionals regarding resuscitation intervention for the terminally ill. The Canadian Nurse, 80(6), 24.

Jones, K. R. (1992). Maintaining quality in a changing environment. Dermatological Nursing, 4(1), 35-39.

Jonsen, A. R. (1989). Bentham in a box. Technological assessment and health care allocation. National Forum. Phi Kappa Phi Journal, 69(4), 33-35.

Kastenbaum, R. J. (1991). Death, society, and human experience. New York: Macmillan.

Keffer, M. J. (1990). Ethical decisions in nursing: The do-not-resuscitate decision. Unpublished doctoral dissertation, University of Illinois at Chicago, Health Sciences Center.

Kirchhoff, K. T., Sylwestrak, M. L., Chenelly, S., & McLane, C. (1988). Evaluation of adherence to policy and procedures. Nursing Management, 19, 51-54.

Kleinbaum, D. G., & Kupper, L. L. (1978). Applied regression analysis and other multivariable methods. Boston, MA: Duxbury.

Klir, G. J. (1972). Preview: The polyphonic general systems theory. In G. J. Klir (Ed.), Trends in General Systems Theory (pp. 1-5). New York: John Wiley & Sons.

Kolcaba, K. Y. (1991). A taxonomic structure for the concept comfort. IMAGE: Journal of Nursing Scholarship, 23(4), 237-240.

Kouwenhoven, W. B., Jude, J. R., & Knickerbocker, G. G. (1960). Closed-chest cardiac massage. JAMA, 173, 1064-1067.

Lamm, R. D. (1989). High technology health care. National Forum, The Phi Kappa Phi Journal, 69(4), 14-17.

Lang, N. M., & Marek, K. D. (1991). The policy and politics of patient outcomes. Journal of Nursing Quality Assurance, 5(2), 7-12.

Latimer, E. (1991). Auditing the hospital care of dying patients. Journal of Palliative Care, 7(1), 12-17.

Ley, D. C. (1989). The elderly and palliative care. Journal of Palliative Care, 5(4), 43-58.

Levinson, W., Shepard, M. A., Dunn, P. M., & Parker, D. F. (1987). Cardiopulmonary resuscitation in long-term care facilities: A survey of do-not-resuscitate orders in nursing homes. Journal of the American Geriatric Society, 35(12), 1059-1062.

Lewandowski, W., Daly, B., McClish, D. K., Juknialis, B. W., & Younger, S. J. (1985). Treatment and care of "do not resuscitate" patients in a medical intensive care unit. Heart & Lung, 14(2), 175-181.

Lindley-Davis, B. (1991). Process of dying. Defining characteristics. Cancer Nursing, 14(6), 328-333.

Lindsay, E. (1991). Life at all costs. Canadian Nurse Journal, 87(3), 16-18.

Lipton, H. L. (1986). Do-not-resuscitate decisions in a community hospital. Incidence, implications, and outcomes. JAMA, 256(9), 1164-1169.

Lo, B., McLeod, G. A., & Saika, G. (1986). Patient attitudes to discussing life-sustaining treatment. Archives of Internal Medicine, 146, 1613-1615.

Lo, B., Saika, G., Strull, W., Thomas, E., & Showstack, J. (1985). 'Do not resuscitate' decisions. A prospective study at three teaching hospitals. Archives of Internal Medicine, 145, 1115-1117.

Longo, D. R., Burmeister, R., & Warren, M. (1988a). "Do not resuscitate": Policy and practice in the long-term care setting. The Journal of Long-Term Care Administration, 16(11), 5-11.

Longo, D. R., Warren, M., Roberts, J. S., & Dunlop, G. R. (1988b). Extent of DNR policies varies across healthcare settings. Health Progress, June , 66-73.

MacDonald, N. (1992). Research - a neglected area of palliative care. Journal of Palliative Care, 8(1), 54-58.

Macklin, R. (1989). Ethical principles, individual rights, and medical practices. National Forum. The Phi Kappa Phi Journal, 69(4), 25-27.

MacNee, W. (1992). Predictors of survival in patients treated with long-term oxygen therapy. Respiration, 59(supplement 2), 5-7.

Mahrenholz, D. A. (1991). Outcomes research and nurses. NursingConnections, 4(1), 58-61.

Malette v. Shulman. (1990). 72 OR(2d) 417 (Ont CA).

Marshall, V. M. (1980a). Last chapters. A sociology of aging and dying. Monteray, CA: Brooks/Cole.

Marshall, V. W. (1980b). No exit. An interpretive perspective on aging (pp. 51-60). In V. M. Marshall (Ed.), Aging in Canada: Social perspectives. Don Mills, ON: Fitzhenry & Whiteside.

Marshall, P. A. (1992). Anthropology and bioethics. Medical Anthropology Quarterly, 6(1), 49-73.

McCormick, K. (1992). Areas of outcome research for nursing. Journal of Professional Nursing, 8(2), 71.

McCusker, J. (1984). The terminal period of cancer: Definition and descriptive epidemiology. Journal of Chronic Diseases, 37, 377-385.

McPhail, A., Moore, S., O'Connor, & Woodward, C. (1981). One hospital's experience with a "do not resuscitate" policy. Canadian Medical Association Journal, 125, 830-836.

McRae, M. E., & Chapman, J. S. (1991). Holding death at bay: the experience of spouses of patients undergoing cardiovascular surgery. Canadian Journal of Cardiovascular Nursing, 2(2), 14-20.

Miles, S. H., & August, A. (1990). Courts, gender, and "the right to die". Law, Medicine & Health Care, 18(1-2), 85-95.

Miles, S. H., Cranford, R., & Schultz, A. L. (1982). The do-not-resuscitate order in a teaching hospital. Annals of Internal Medicine, 96, 660-664.

Miles, S. H., & Moldow, D. G. (1984). The prevalence and design of hospital protocols limiting medical treatment. Archives of Internal Medicine, 144, 1841-1943.

Miles, S. H., & Ryden, M. B. (1985). Limited-treatment policies in long-term care facilities. Journal of the American Geriatrics Society, 33, 707-710.

Mitroff, I. (1983). Stakeholders of the organizational mind. San Francisco, CA: Jossey-Bass.

Molloy, D. W., & Guyatt, G. H. (1991). A comprehensive health care directive in a home for the aged. Canadian Medical Association Journal, 145(4), 307-311.

Moser, C. A. & Kalton, G. (1972). Survey methods in social investigation (2nd ed.). London: Heinemann Educational Books.

Mumma, C. M., & Benoliel, J. Q. (1984-85). Care, cure, and hospital dying trajectories. Omega, 15(3), 275-288.

Musgrave, C. F. (1990). Terminal dehydration. To give or not to give intravenous fluids? Cancer Nursing, 13(1), 62-66.

National Advisory Council on Aging. (1989). 1989 and beyond. Challenges of an aging Canadian Society. Canada: Minister of Supply and Services.

Nie, N. H., Hull, C. H., Jenkins, J. G., Steinbrenner, K., & Bent, D. H. (1975). Statistical package for the social sciences(2nd ed.). New York: McGraw-Hill.

Noddings, N. (1984). An ethic of caring. In Caring: A feminine approach to ethics and moral education (pp. 79-103). Berkley, CA: University of California Press.

Norberg, A., Asplund, K., & Waxman, H. (1987a). Withdrawing feeding and withholding artificial nutrition from severely demented patients. Interviews with caregivers. Western Journal of Nursing Research, 9(3), 348-356.

Norberg, A., & Hirschfeld, M. (1987). Feeding of severely demented patients in institutions: Interviews with caregivers in Israel. Journal of Advanced Nursing, 12, 551-557.

Norberg, A., Norberg, B., Gippert, H., & Bexell, G. (1980b). Ethical conflicts in long-term care of the aged: nutritional problems and the patient-care workers relationship. British Medical Journal, 281, 377-378.

Noyes, R., Jochimsen, P. R., & Travis, T. A. (1977). The changing attitudes of physicians toward prolonging life. Journal of the American Geriatrics Society, 25(10), 470-474.

Oliver, D. (1984, Sept. 15). Terminal dehydration. The Lancet, 631.

Omery, A. (1989). Values, moral reasoning, and ethics. Nursing Clinics of North America, 24(2), 499-508.

Oppenheim, A.N. (1966). Questionnaire design and attitude measurement. New York: Basic Books.

Ott, B. B., & Nieswiadomy, R. M. (1991). Support of patient autonomy in the do not resuscitate decision. Heart & Lung, 29(1), 66-72.

Pearlman, R. A., Inui, T. S., Carter, W. B. (1982). Variability in physician bioethical decision-making. Annals of Internal Medicine, 97, 420-425.

Pearlman, R. A., & Jonsen, A. (1985). The use of quality-of-life considerations in medical decision making. Journal of the American Geriatrics Society, 33(5), 344-352.

Pearlman, R. A., & Uhlmann, R. F. (1988). Quality of life in chronic diseases: perceptions of elderly patients. Journal of Gerontology: Medical Sciences, 43(2), M25-M30.

Peck, A., Cohen, C. E., & Mulvihill, M. N. (1990). Long-term enteral feeding of aged demented nursing home patients. Journal of the American Geriatrics Society, 38, 1195-1198.

Penticuff, J. H. (1991). Conceptual issues in nursing ethics research. Journal of Medicine and Philosophy, 16(3), 235-258.

Perakyla, A. (1991). Hope work in the care of seriously ill patients. Qualitative Health Research, 1(4), 407-433.

Perkins, H. S. (1986). Ethics at the end of life: Practical principles for making resuscitation decisions. Journal of General Internal Medicine, 1, 170-176.

Perry, S. W., Schwartz, H. I., & Amchin, J. (1986). Determining resuscitation status: A survey of medical professionals. General Hospital Psychiatry, 8(3), 198-202.

Pilcher, D. M. (1990). Data analysis for the helping professions. A practical guide. Newbury Park, England: Sage Publications.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). Deciding to forgo life-sustaining treatment. Washington, DC: U.S. Government Printing Office.

Putt, A. M. (1978). Introduction to general systems theory. In A. M. Putt (Ed.), General Systems Theory Applied to Nursing (pp. 1-6). Boston: Little, Brown & Co.

Quill, T. E. (1989). Utilization of nasogastric feeding tubes in a group of chronically ill, elderly patients in a community hospital. Archives of Internal Medicine, 149, 1937-1941.

Quill, T. E., Stankaitis, J. A., & Krause, C. R. (1986). The effect of a community hospital resuscitation policy on elderly patients. New York State Journal of Medicine, 86, 622-625.

Rich, R. F. (1990). Policymaking for science and technology. National Forum, The Phi Kappa Phi Journal, 71(4), 16-19.

Robertson, G. B. (1991). Advance directives - a legal view. Health Law Review, 1(1), 3-6.

Rousseau, P. C. (1991). How fluid deprivation affects the terminally ill. RN, 54(1), 73-77.

Rozovsky, L. E., & Rozovsky, F. A. (1985). No code orders and the law. Canadian Critical Care Nursing Journal, 2(2), 16-18.

Schmitz, P. (1991). The process of dying with and without feeding and fluids by tube. Law, Medicine & Health Care, 19(1-2), 23-26.

Schwartz, D. A., & Reilly, P. (1986). The choice not to be resuscitated. Journal of the American Geriatrics Society, 34, 807-811.

Seale, C. (1992). Community nurses and the care of the dying. Social Sciences and Medicine, 34(4), 375-382.

Shelley, S. I., Zahorchak, R. M., Gambrill, C. D. S. (1987). Aggressiveness of nursing care for older patients and those with do-not-resuscitate orders. Nursing Research, 36(3), 157-162.

Shields, G. (1989). The treatment of formal patients in a city hospital. AARN Newsletter, 45(7), 27-28.

Shmerling, R. H., Bedell, S. E., Lilienfeld, A., & Delbanco, T. L. (1988). Discussing cardiopulmonary resuscitation: A study of elderly outpatients. Journal of General Internal Medicine, 3, 317-321.

Skelton, D. (1987). Grapes or raisins.... A geriatrician's reflections upon the future of health care for the elderly. Edmonton, AB: Alberta Hospital Association.

Skelton, E. (1990). Rights of patients strengthened with court ruling, experts say. The Globe and Mail, April 2, pp. A4.

Slater, P. (1987). The good death: Registered nurses' concerns about ethical issues. The Australian Journal of Advanced Nursing, 4(4), 16-28.

Smith, S. K. (1988). An analysis of the phenomenon of deterioration in the critically ill. IMAGE: Journal of Nursing Scholarship, 20(1), 12-15.

Smith, D. H., & Veatch, R. M. (Eds.). (1987). Guidelines on the termination of life-sustaining treatment and the care of the dying. Bloomington, IN: Indiana University Press.

Starr, T. J., Pearlman, R. A., & Uhlmann, R. F. (1986). Quality of life and resuscitation decisions in elderly patients. Journal of Internal General Medicine, 1, 373-379.

Statistics Canada. (1991). Canada Yearbook. 1992. Ottawa: Author.

Steiber, S. R. (1987). Right to die: Public balks at deciding for others. Hospitals, March 5, 72.

Steinbrook, R., Lo, B., Moulton, J., Saika, G., Hollander, H., & Volberding, P. A. (1986). Preferences of homosexual men with Aids for life-sustaining treatment. The New England Journal of Medicine, 314(7), 457-460.

Stewart, A. G., & Howard, P. (1992). Indications for long-term oxygen therapy. Respiration, 59(supplement 2), 8-13.

Storch, J. (1982). Patient rights. Ethical and legal issues in health care and nursing. Toronto: McGraw-Hill Ryerson.

Sudman, S., & Bradburn, N. M. (1986). Asking questions. A practical guide to questionnaire design. San Francisco, CA: Jossey-Bass.

Taffet, G. E., Teasdale, T. A., & Luchi, R. J. (1988). In-hospital cardiopulmonary resuscitation. JAMA, 260(14), 2069-2072.

Thom, A. (1985). Who decides? Nursing Times, 85(2), 35-37.

Tittle, M. B., Moody, L. & Becher, M. P. (1992). Nursing requirements of patients with DNR orders in intensive care units. Heart and Lung: Journal of Critical Care, 21(3), 235-242.

Toulmin, S. (1981). The tyranny of principles. Hastings Center Report, 11, 31-39.

Townsend, M. B., Vass, B. C., & Defontes, J. (1990). Clarifying resuscitation status: A new approach. Nursing Management, 21(10), 88A-88B.

Turner, J. (1987). Problems of recognizing dehydration in hospital patients. Nursing Times, 83(51), 44.

Uhlmann, R. F., Pearlman, R. A., & Cain, K. C. (1988). Physicians' and spouses' predictions of elderly patients' resuscitation preferences. Journal of Gerontology: Medical Sciences, 48(5), M115-M121.

Vincent, J. J. (1990). European attitudes towards ethical problems in intensive care medicine: Results of an ethical questionnaire. Intensive Care Medicine, 16, 256-264.

von Bertalanffy, L. (1968). General systems theory - A critical review. In W. Buckley (Ed.), Modern Systems Research for the Behavioral Scientist (pp. 11-30). Chicago, IL: Aldine Pub. Co.

Watson, W. H., & Maxwell, R. J. (1977). Human aging and dying. A study of sociocultural gerontology. New York: St. Martin's Press.

Watts, D. T., Cassel, C. K., & Hickam, D. H. (1986). Nurses' and physicians' attitudes toward tube-feeding decisions in long-term care. Journal of the American Geriatrics Society, 34(8), 607-611.

Wear, S. (1991). The irreducibly clinical character of bioethics. The Journal of Medicine and Philosophy, 16, 71-91.

Wetle, T., Levkoff, S., Cwikel, J., & Rosen, A. (1988). Nursing home resident participation in medical decisions: Perceptions and preferences. The Gerontologist, 28, 32-38.

Wilks, E. (1984). Dying now. Lancet, 1, 950-952.

Wilson, D. M. (1991). Long-term tube feeding practices and involvement of nurses in tube feeding decisions. Canadian Journal on Aging, 10(4), 333-344.

Wilson, D. M. (1992). Survey Results of Edmonton-area health care facility policy and procedure manuals. (unpublished manuscript, University of Alberta, Edmonton, Alberta).

Wilson, D. M. (in press). Supporting life through tube feeding: Factors influencing surrogate decision-making. Canadian Journal on Aging.

Winkler, E. R. (1987). The morality of withholding food and fluid. Journal of Palliative Care, 3(2), 26-30.

Witte, K. L. (1984). Variables present in patients who are either resuscitated or not resuscitated in a medical intensive care unit. Heart & Lung, 13(2), 159-163.

Wolff, M. L., Smolen, S., & Ferrara, L. (1985). Treatment decisions in a skilled-nursing facility: discordance with nurses' preferences. Journal of the American Geriatrics Society, 33, 440-445.

Wolfsen, H. C., Kozarek, R. A., Ball, T. J., Patterson, D. J., Botoman, V. A., & Ryan, J. A. (1990). Long-term survival in patients undergoing percutaneous endoscopic gastrostomy and jejunostomy. The American Journal of Gastroenterostomy, 85(9), 1120-1122.

Younger, S. J. (1987). Do-not-resuscitate orders: No longer secret, but still a problem. Hastings Center Report, 17(1), 24-33.

Younger, S.J., Lewandowski, W., McClish, D.K., Juknialis, B.W., Coulton, C. & Bartlett, E.T. (1985). Do not resuscitate orders. Incidence and implications in a medical intensive care unit. JAMA, 253(1), 54-57.

Zerwekh, J. V. (1983). The dehydration question. Nursing 83, 13(1), 46-51.

Zimmerman, J. E., Knaus, W. A., Sharpe, S. M. (1988). The use and implications of DNR orders in intensive care units. Journal of the American Medical Association, 255, 351-354.

Bibliography

American Psychological Association. (1983). Publication manual of the American Psychological Association (3rd ed.). Washington, DC: Author.

Berdie, D. R., & Anderson, J. F. (1974). Questionnaires: Design and use. Metuchen, NJ: The Scarecrow Press.

Converse, J. M. & Presser, S. (1986). Survey questions. Handcrafting the standardized questionnaire. Beverly Hills, CA: Sage.

Kalton, G. (1983). Introduction to survey sampling. London: Sage.

McCallon, E. L., & McCray, E. (1975). Designing and using questionnaires. Austin, TX: Learning Concepts.

Platek, R., Pierre-Pierre, F. K., & Stevens, P. (1985). Development and design of survey questionnaires. Ottawa: Statistics Canada.

Appendices

Appendix A

Survey Questionnaire of DNR Policies in Accredited Alberta Acute Care Hospitals and Long-Term Care Facilities

Survey of DNR Policies in Alberta Acute Care Hospitals and Long-Term Care Facilities

Please answer the following questions,returning them in the enclosed envelope by November 15,1992.

1. Is your facility PRIMARILY: CHECK ONE

   (a) ☐ an Acute Care Hospital

   (b) ☐ a Long-Term Care Facility

   (c) ☐ other, such as _____

2. What is the size of your facility? (exclude bassinets) CHECK ONE

   (a) ☐ 1 - 49 beds (d) ☐ 200 - 299 beds

   (b) ☐ 50 - 99 beds (e) ☐ 300 - 499 beds

   (c) ☐ 100 - 199 beds (f) ☐ 500 + beds

3. Is your facility currently accredited by the Canadian Council of Health Facilities? CHECK ONE

   (a) yes ☐ (b) no ☐

4. Does your facility have intensive care beds and the associated intensive care technology? (such as ventilators/respirators, cardiac monitors, etc.) CHECK ONE

   (a) yes ☐ (b) no ☐

★ Please **refer to Your Policy and Procedure Manuals now**, and use them to answer the following questions.

★ A **POLICY** IS DEFINED AS ANY WRITTEN INFORMATION IN YOUR POLICY AND PROCEDURE MANUALS AVAILABLE TO FACILITY STAFF.

5. Does your facility have a written Do Not Resuscitate (DNR), No CPR, or a similar policy? A DNR policy allows patients to die without cardio-pulmonary (or other) resuscitation.

   (a) ☐ yes date developed: _____ continue at question 6 (next page)

   (b) ☐ no, but there is an informal DNR policy, as written DNR orders are used in our facility.

   (c) ☐ no, but it is being drafted.

   (d) ☐ no, no policy.

   If no, please skip to question 16 after completing the following question: What factors or influences may have contributed to your facility not having a policy?

   _____

   _____

continues on next page ☞

6. IF YOUR FACILITY HAS A DNR POLICY, Who was involved in developing this DNR policy? CHECK ALL THAT APPLY

(a) ☐ medical representatives

(b) ☐ nursing representatives

(c) ☐ administrative representatives (non-nursing, non-medical)

(d) ☐ others such as: _____

7. What influenced the development of your DNR policy? Another way of asking this is "what factors or reasons caused the DNR policy to be written?"

PLEASE COMMENT IN AS MUCH DETAIL AS POSSIBLE.

8. IF YOUR FACILITY HAS A DNR POLICY, were you personally involved in its development?

(a) yes ☐ (b) no ☐

continues on back of this page ☞

9. IF YOUR FACILITY HAS A DNR POLICY, Does your DNR policy have any of the following content? CHECK ALL THAT APPLY

(a) ☐ clinical patient criteria to make a DNR decision
(b) ☐ using a patient's living will to learn of treatment preferences
(c) ☐ using this living will to learn who may be a surrogate decision-maker
(d) ☐ using this living will to learn who should not be a surrogate decision-maker
(e) ☐ when the DNR decision-making is to occur, such as:

_____

(f) ☐ educational or informational requirements of the patient, family or others
(g) ☐ the discussion with patient, family or others is recorded in the chart
(h) ☐ the doctor must write a DNR order in the chart
(i) ☐ the DNR order must be rewritten on a regular basis,

if so, how often: _____

(j) ☐ the DNR decision is reviewed on a regular basis:

if so, how often: _____

(k) ☐ DNR decision-making is repeated on each admission
(l) ☐ the patient and/or family, significant others, legal guardian can refuse life supporting treatment
(m) ☐ the patient and/or family, significant others, legal guardian can refuse to accept a DNR decision
(n) ☐ only a physician can rescind/change a DNR order to allow resuscitation to occur

(o) ☐ other, such as: _____

10. ACCORDING TO THE DNR POLICY, WHO is the PRIMARY/MAIN decision-maker when the patient is COMPETENT? CHECK ONE

(a) ☐ competent patient
(b) ☐ patient's primary physician
(c) ☐ another person(s), such as: _____

11. ACCORDING TO THE DNR POLICY, WHO MAY be involved in the DNR decision when the patient is COMPETENT? CHECK ALL THAT APPLY

(a) ☐ patient
(b) ☐ primary physician
(c) ☐ any physician
(d) ☐ Ethics Committee
(e) ☐ multidisciplinary team
(f) ☐ family member(s)
(g) ☐ significant other(s)
(h) ☐ member of the clergy
(i) ☐ one or more nurse(s)
(j) ☐ other specify:

_____

continues on next page ☞

12. ACCORDING TO THE DNR POLICY, WHO is the PRIMARY/MAIN decision-maker when the patient is INCOMPETENT? CHECK ONE

(a) ☐ the patient (the decision is based on a patient's prior verbal or written wishes/preferences/values)
(b) ☐ the patient's primary physician
(c) ☐ another person(s), such as: _____

_____

13. ACCORDING TO THE DNR POLICY, WHO also may be involved in the DNR decision when the patient is INCOMPETENT? CHECK ALL THAT APPLY

(a) ☐ the patient, via previous verbal preferences/wishes
(b) ☐ the patient, via previous written preferences/wishes
(c) ☐ the patient, previous verbal refusal of treatment
(d) ☐ the patient, current behaviours of treatment refusal
(e) ☐ the patient's primary physician
(f) ☐ another physician
(g) ☐ family member(s)
(h) ☐ significant other(s)
(i) ☐ Ethics Committee
(j) ☐ nurse(s)
(k) ☐ clergy
(l) ☐ multidisciplinary team
(m) ☐ public guardian
(n) ☐ legal guardian
(o) ☐ other persons, such as: _____

_____

continues on back of this page ☞

14. IF THERE IS A DNR POLICY, does that policy or another policy ALSO direct that decisions be made about the use of other life supporting technologies?

(a) ☐ yes, date developed: _____

(b) ☐ no, but this occurs/is the practice in our facility (PLEASE SKIP TO QUESTION 16)

(c) ☐ no, but this policy is in draft form (PLEASE SKIP TO QUESTION 16)

(d) ☐ no, no policy (PLEASE SKIP TO QUESTION 16)

15. IF YOU ANSWERED YES TO QUESTION 14, what SPECIFIC care is preplanned (IN ADDITION TO CPR) ? CHECK ALL THAT APPLY

(a) ☐ defibrillation
(b) ☐ intubation and mechanical ventilation
(c) ☐ oxygen therapy by mask, tent, or prongs
(d) ☐ intravenous fluids and electrolytes
(e) ☐ antibiotics
(f) ☐ medications other than antibiotics
(g) ☐ transfer to another facility
(h) ☐ total parenteral nutrition (TPN)
(i) ☐ enteral tube feeding
(j) ☐ hypodermoclysis
(k) ☐ other, such as: _____

_____

16. Does your facility's mission or philosophy statement refer to patients who are dying or who are terminally ill? CHECK ONE

(a) ☐ yes, date developed: _____
(b) ☐ no, but it is being rewritten with this in it
(c) ☐ no

17. If you have a separate NURSING mission or philosophy statement, does this refer to patients who are dying or who are terminally ill? CHECK ONE

(a) ☐ yes, date developed: _____
(b) ☐ no, but it is being rewritten with this in it
(c) ☐ no
(d) ☐ not applicable

continues on next page ☞

★ **I would also like to ask your opinion about the following two items.**

18. Do you feel this DNR policy or policies represent what is actually practised in your health care facility?

(a) ☐ yes
(b) ☐ no
(c) ☐ not applicable

Please comment:

_____

_____

_____

_____

19. Do you foresee changes in life support policies and practices in Acute Care Hospitals and Long-Term Care Facilities in Alberta?

(a) ☐ yes
(b) ☐ no

Please comment:

_____

_____

_____

_____

Thank you! Please return the questionnaire in the attached envelope to:

Donna Wilson,
C/O Faculty of Nursing,
3rd Floor CSB,
University of Alberta,
Edmonton, Alberta,
T6G 2G3.

Would you like to receive a copy of my research findings? If so, please write to the above address requesting a copy. To ensure anonymity, this letter should not be returned with the questionnaire. The report will be sent in the fall of 1993. A copy of the report will be given to the AARN, AHA, and the U of A Library.

Appendix B

Cover Letter
Requesting Senior Nursing Administrators in Accredited Acute Care and Long-Term Care Facilities in Alberta to Participate in the Research Study

October 15, 1992

Dear Health Care Executive,

I am surveying DNR policies in Acute Care Hospitals and Long-Term Care Facilities in Alberta. Would you please contribute to this study by completing the enclosed anonymous questionnaire?

The questionnaire has 19 questions, and should take less than 20 minutes to complete. This questionnaire requires that you refer to your facility's policy manual(s). I am asking that the completed questionnaires be returned to me in the enclosed stamped envelope by November 15, 1992.

I am undertaking this study because little is known about life support policies and practices in Canada. Each health care facility in Canada is not required to, but can, develop life support policies. Health care administrators and others would benefit from learning more about life support policies and the influences for these policies.

Your facility's name was selected from the 1991 Canadian Hospital or Long-Term Care Directory. Your participation is voluntary and confidential. Your name and your facility's name will never be used in any reports. Only I will know to whom this questionnaire was sent. The questionnaire has a number on it, so I can determine how many Acute Care and Long-Term Care Facilities have returned the questionnaire.

I would be pleased to answer any questions you have about this study. You can reach me at the address and telephone number listed at the bottom of this page. You can also contact my PhD supervisor, Dr. Al MacKay if you have any concerns. He may be reached at the Department of Educational Administration, Faculty of Education, Seventh Floor, Education North Building, U of A, Edmonton, AB T6G 2G5 (492-3751). For your information, the U of A Department of Educational Administration has granted ethical approval for this study.

I will complete this study by August, 1993 and plan to publish the results soon after. A copy of my complete research study will be given to the Alberta Association of Registered Nurses, the Alberta Healthcare Association, and the U of A library system. If you wish to have a copy of the study's findings, please write me and I will be pleased to send you a copy.

Thank you very much for your assistance. Your interest and patience is very much appreciated.

Sincerely,

Donna Wilson, RN, MSN
PhD Student, Educational Administration, University of Alberta
c/o Faculty of Nursing
Third Floor Clinical Sciences Building
University of Alberta
Edmonton, Alberta T6G 2G3 Telephone # 492-5574

Appendix C

Follow-up Letter
To Senior Nursing Administrators
of Acute Care and Long-Term Care Facilities

November 25, 1992

Dear Administrator,

In October a questionnaire surveying DNR policies in Alberta was sent to you. This is a reminder letter requesting your assistance with completing and returning the questionnaire. I have sent an additional questionnaire for your convenience.

If you have completed and returned the questionnaire I would like to thank you for your assistance. There has been a great deal of interest in this study, and I am eager to analyze the findings.

If you have not completed the questionnaire, I encourage you to do so now. No doubt you have many such requests for time out of your busy schedule. Your participation is important for both the validity and usefulness of this study. The deadline for completion of the questionnaire has been extended to December 31, 1992.

I would also like to remind you that if you do send in a questionnaire and then wish to withdraw your questionnaire from this study, you can do so by contacting me at the following address and telephone number.

Thank you again for your interest and assistance with this study!

Seasons Greetings,

Donna Wilson, RN, MSN

PhD Student, Educational Administration, University of Alberta

c/o Faculty of Nursing
Third Floor Clinical Sciences Building
University of Alberta
Edmonton, Alberta T6G 2G3 Telephone # 492-5574

Appendix D

Patient Care Record Review Data Collection Instrument

Patient Care Record Review Data Collection Instrument

Facility ID #: _____

Patient Identification Number: _____

_____

Patient age: _____

Date of Death: _____

Date of Admission: _____

Cause of Death: _____

_____

Location of Death: _____

DNR order, Y/N, date: _____

_____

DNR influences: _____

_____

Technology used at end-of-life: _____

_____

_____

_____

Influences for treatment decisions: _____

_____

_____

_____

_____

Adherence to DNR policy: _____

_____

Appendix E

Introductory Letter to Nurses and Physicians

Physician's or Nurse's name
c/o nursing unit or office
facility name
city, province, postal code date

Dear (Physician or Nurse),

I am doing a study to find what influences end-of-life patient care decisions. I have finished a chart review of all patients who recently passed away in your facility. You cared for one of these patients. Would you please help me with this study by telling me about the factors that affected decisions made for that patient? One short conversation is all that is required.

I am doing this study because life support decisions can be very difficult. Understanding what affects these decisions may be helpful to Canadian nurses and physicians. Some research has addressed this topic, but so similar study has been undertaken in Canada.

I will finish this study by August, 1993 and plan to publish the results soon after. Your name and your facility's name will not be used in any reports. No one, except me, will ever know that you were interviewed.

Your facility and the University Ethics Committee have both granted ethical and administrative approval for this study. If you do have questions, however, you can speak to me or my research supervisor, Dr. Al MacKay. Our addressed and telephone numbers are at the bottom of this page.

You do not have to agree to be interviewed. If you decide to be interviewed now, and change your mind later, just call and tell me this. If you agree to be interviewed, please sign and return the consent form. I will be in touch with you before or shortly after the New Year to arrange an interview.

Thank you.

Sincerely,

Donna Wilson, RN, MSN

PhD student, Educational Administration, University of Alberta

Donna Wilson, RN, MSN
Faculty of Nursing
Third Floor Clinical Sciences Building
University of Alberta
Edmonton, Alberta T6G 2G3
☎ 492-5574

Dr. Al MacKay
Department of Educational
Administration
Faculty of Education
Eighth Floor Education South Building
University of Alberta
Edmonton, AB T6G 2G5
☎ 492-3751.

Appendix F

Consent Form
For Nurses and Physicians

CONSENT FOR THE RESEARCH STUDY TITLED:

Influences for End-Of-Life Treatment Decisions

The researcher who is doing this study is:

Donna Wilson, RN, MSN
PhD Student and
Assistant Professor
Faculty of Nursing
Third Floor Clinical Sciences Building
University of Alberta
Edmonton, Alberta T6G 2G3
☎ 492-5574

Supervisor of Donna Wilson
Dr. Al MacKay
Department of Educational Administration
Faculty of Education
Eighth Floor Education South Building
University of Alberta
Edmonton, AB T6G 2G5
☎ 492-3751.

Purpose of this study: To gain information about the influences affecting end-of-life treatment decisions. Some American studies have investigated end-of-life treatment influences, but there does not appear to have been any Canadian research to identify the influences for care provided to a patient in the last days of their life.

Procedures and risks: An interview is planned. An interviewer (myself) will ask you one main question. This question is "What influenced the decisions that were made about end-of-life care for a deceased patient?" This interview may take as little as five minutes or as long as 30 minutes depending on the conversation that develops.

There should be no risk or harm from this study. Only the information that you are willing to share will be noted and used for research purposes. All information should be gathered by the end of February, 1993.

Voluntary participation: You do not have to participate in this study. If you change your mind about being involved in the study after you have been interviewed please call me or write me and the information you gave me will be destroyed.

Confidentiality: Your name, the facility's name, and all information is confidential. No report will ever list your name or facility's name. No one, other than myself, will know you were interviewed. Reports and publications about this study will only describe your facility as an Acute or Long-Term Care facility in Alberta and will only describe you by your profession.

Any questions you have will be answered prior to the interview.

You have been sent two copies of this consent form. If you agree to be interviewed, please sign one copy and return it via the stamped envelope. You can keep one copy and the introductory letter.

Participant's statement: I have read this information and give my consent to be interviewed for this study.

Signature _____ Date _____

What would be the best time and place to reach you? Thank you. Donna

---

Appendix G

Prerequisite Discussion Guidelines

Prerequisite Discussion Guidelines

The following discussion guidelines will be used prior to the interview of each nurse and physician by the principal investigator.

1. My name is Donna Wilson. I am doing a PhD research study that is investigating the influences for end-of-life treatment decisions.

2. A letter informing you about my study was sent to you. Did you receive the letter?

3. The information I am seeking is the influences for end-of-life treatment decisions. I am interested in what factors or influences affected the choices for treating or not treating patients prior to their death.

4. Your name was obtained through a chart review of recently deceased patients in your facility.

5. This study has been approved by the Ethics Committee of the Department of Educational Administration, Faculty of Education in the University of Alberta, and also by your health care facility.

6. Do you have any concerns or questions about the study?

7. Your participation is voluntary, you do not have to participate. Even if you do decide to be interviewed you can reach me later to withdraw from the study.

8. If you do participate in the study I will ask you about the influences affected the end-of-life treatment decisions for a specific patient that I will name. The discussion may take as little as five minutes. If numerous life supporting interventions were used the discussion may be longer as there may have been different influences for different interventions.

9. Your name and facilities name will never be used in any reports or publications either now or later. You and others who will be interviewed with be called a health care professional, and will be said to be associated with an AC or LTC facility in Alberta.

10. you may contact my research supervisor if you have any questions or concerns about this study: Dr. Al MacKay, Department of Educational Administration, Faculty of Education Eighth Floor Education South Building, University of Alberta, Edmonton, AB T6G 2G5, ☎ 492-3751.

11. do you verbally agree to participate in this study? Have you read and completed the consent form also mailed to you?

The interview will proceed if the nurse or physician agrees to participate. The discussion will end if not.

Appendix H

Interview Data Collection Instrument

Interview Data Collection Instrument

Facility ID #: _____

Patient identification number: _____

_____

Treatment decisions (DNR and technology during the EOL): _____

_____

_____

Involvement in decisions: yes ☐ no ☐

Rationale for treatment decisions: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Doctor / Nurse: _____

_____

_____

Appendix I

Evaluation of Survey Questionnaire

Evaluation of Survey Questionnaire

Please be FRANK! Your honest opinion is needed and will be much appreciated. Thank you again for your help! Donna Wilson

1. Does the questionnaire, overall, ask the most important and relevant questions about written life support policies?
   yes ☐
   no ☐

2. Are the instructions on the cover letter understandable?
   yes ☐
   no ☐

3. Are the instructions on the questionnaire understandable?
   yes ☐
   no ☐

4. Are any questions difficult to understand?
   yes ☐
   no ☐

   If yes, which ones, and any ideas on how to improve them?

   _____

5. Are any questions unnecessary and should be deleted?
   yes ☐
   no ☐

   _____

6. Are any questions missing?
   yes ☐
   no ☐

   _____

7. How long did it take you to complete the questionnaire? _____

8. Is the questionnaire:
   too long ☐
   too short ☐
   about right in length ☐

9. Who do you think this questionnaire should be sent to in hospitals and long-term care facilities? (I am concerned about having a good return rate from organizations across Canada)
   senior nursing administrator ☐
   chief of medical staff ☐
   chief executive officer ☐
   other ☐ _____

10. Other comments:

    _____

    _____